

**The Gatekeepers of Palliative Care: A systematic mixed studies review of oncologists' perceptions and attitudes towards palliative care for advanced cancer patients**

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## **Abstract**

**Background:** Early palliative care has been shown to optimize a variety of different aspects of cancer care including symptom management, psychosocial support, spiritual care and decision-making. Despite these benefits and the increasing availability of palliative care services, the majority of cancer patients are only referred to palliative care in the late, terminal stages of disease. As the gatekeepers of palliative care, oncologists can offer a wealth of insight into why cancer patients are not being referred as early and as often as they should. **Objectives:** The main purpose of this thesis is to explore oncologists' perceptions and attitudes toward palliative care in order to better understand the physician-level barriers to early palliative care referral. **Methods:** This thesis contains of two related manuscripts. The first manuscript consists of a systematic mixed studies review and narrative synthesis of the current literature investigating oncologists' perceptions and attitudes toward palliative care for cancer patients. The second manuscript expands on the first manuscript by examining oncologist-driven models of palliative care referral from an ethical perspective. **Results:** Twenty-one studies met the inclusion criteria for the systematic review. Themes describing oncologists' perceptions of palliative care include: 1) the value of palliative care, 2) the timing of palliative care referral, 3) the role of the palliative care provider, 4) the coordination of care, 5) the philosophy of care and 6) the impact of palliative care referral on the patient. The ethical analysis found that, owing to oncologists' heterogeneous perceptions of palliative care, the current oncologist-driven models of palliative care referral are unethical and need to be improved. **Conclusions:** The delays in referral to palliative care are likely due to the conflicting professional cultures of oncology and palliative care, as well as a

lack of provider knowledge about the appropriate use and timing of palliative care referral.

Understanding these physician-level barriers to early referral is crucial to inform the development of strategies to increase collaboration between oncology and palliative care teams and improve the early provision of palliative care for advanced cancer patients.

## **Résumé**

**Contexte:** La recherche démontre que les soins palliatifs précoces permettent d'améliorer divers aspects des soins du cancer, notamment l'intensité des symptômes, le soutien psychosocial, les soins spirituels et la prise de décision. Malgré ces avantages et la disponibilité croissante des services de soins palliatifs, la majorité des patients atteints de cancer sont référés à l'équipe de soins palliatifs seulement quand ils sont en fin de vie. En tant que « gardiens » de soins palliatifs, les oncologues peuvent nous fournir des renseignements importants sur les raisons pour lesquelles les patients atteints de cancer ne sont pas référés assez tôt et assez souvent. **Objectifs:** Le but principal de cette thèse est d'examiner les perceptions et les attitudes des oncologues envers les soins palliatifs afin de mieux comprendre les obstacles au niveau des médecins qui empêchent l'introduction des soins palliatifs précoces. **Méthodes:** Cette thèse contient deux manuscrits. Le premier manuscrit est une revue systématique et une synthèse narrative des études qualitatives, quantitatives et à méthodes mixtes portant sur les perceptions et les attitudes des oncologues envers les soins palliatifs pour les patients atteints de cancer. Le deuxième manuscrit ajoute au premier manuscrit en examinant, d'un point de vue éthique, les modèles actuels de soins palliatifs qui dépendent des oncologues comme « gardiens » des services de soins palliatifs. **Résultats:** Au total, 21 études répondaient aux critères d'inclusion de la revue systématique. Les thèmes décrivant les perceptions des oncologues envers les soins palliatifs comprennent : 1) la valeur des soins palliatifs, 2) le moment approprié pour l'introduction des soins palliatifs, 3) le rôle du médecin qui fournit des soins palliatifs, 4) la coordination des soins, 5) la philosophie des soins et 6) l'impact d'une consultation en soins palliatifs sur le patient. L'analyse éthique a révélé

que, en raison des diverses perceptions des oncologues envers les soins palliatifs, les modèles actuels utilisés pour référer les patients vers des soins palliatifs sont contraires à l'éthique et doivent être améliorés. **Conclusions:** Le retard qui existe entre le diagnostic et l'orientation vers les soins palliatifs est probablement causé par un conflit entre les cultures professionnelles des oncologues et des médecins en soins palliatifs, ainsi qu'un manque de connaissances de la part des oncologues sur le but des services de soins palliatifs et le moment approprié pour orienter les patients vers ces services. Il est important de comprendre les obstacles au niveau des médecins afin de développer des stratégies qui visent à augmenter la collaboration entre les équipes d'oncologie et de soins palliatifs et améliorer l'introduction des soins palliatifs précoces pour les patients atteints de cancer avancé.

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## **List of Abbreviations**

PC – Palliative Care	QOL – Quality of life
WHO – World Health Organization	CCS – Canadian Cancer Society
ASCO – American Society of Clinical Oncology	EOL – End-of-life
NCCN – National Comprehensive Cancer Network	CSPCP – Canadian Society of Palliative Care Physicians
CHPCA – Canadian Hospice Palliative Care Association	RCT – Randomized Controlled Trial
ESMO – European Society of Medical	WPCA – Worldwide Palliative Care Alliance
MBH – Medicare Hospice Benefit	SDM – Shared decision-making
CMA – Canadian Medical Association	MAID – Medical Assistance in Dying
MSR – Mixed Studies Review	

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## **Contribution of Authors**

The research contained in this document was conceptualized and carried out by Caitlin Stoddart under the supervision of Dr. Gillian Bartlett. All material appearing in this thesis was written by Caitlin Stoddart. This thesis is made up of two manuscripts intended for publication, comprising Chapters 3 and 4 of this thesis. All co-authors will be asked to review and approve the manuscripts before they are submitted for publication. The authorship is as follows:

### **Chapter 3: Manuscript 1**

#### **A systematic mixed studies review and narrative synthesis of oncologists' perceptions and attitudes towards palliative care for advanced cancer patients**

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### **Chapter 4: Manuscript 2**

#### **The ethics of palliative care gatekeeping in oncology**

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## **Chapter 1 - Introduction**

In recent years, significant progress has been made in the fight against cancer. The rate of cancer survivorship in Canada has increased from 25% in 1940 to almost 60% today (Canadian Cancer Society, 2017). Particular improvements have been made in breast cancer, with the death rate falling 44% since 1988, and in lung cancer, where it is estimated that 31,660 deaths have been avoided since 1989 (Canadian Cancer Society, 2017). These improvements are the result of disease prevention and control efforts in addition to investments in cancer research totalling over \$500 million dollars annually (Canadian Cancer Research Alliance, 2017). Despite this progress, as the population ages, the number of people diagnosed with cancer continues to rise. In Canada, the average annual number of cases is projected to be 79% higher in 2028-2032 than it was in 2003-2007 (Canadian Cancer Society, 2017).

It is well recognized that cancer and its treatments can cause patients to experience pain and other physical symptoms like nausea, weakness and weight loss (Vainio et al., 1996). The disease, however, can also have significant psychosocial impacts on the patient, their family and members of the community (Page & Adler, 2008). A cancer diagnosis can lead to changes in a patient's responsibilities at work and at home and affect the way they relate to the people around them (Page & Adler, 2008). It might cause patients to miss out on certain social activities and experience depression, anxiety and issues related to intimacy and body image (Holland, 2010). An appreciation for the psychosocial needs of cancer patients has led to a shift in the professional and public interest in the disease. Although survival remains a fundamental goal of cancer care, it is now widely recognized that cancer treatment should be targeting the whole person and not just

the tumor or the disease (Page & Adler, 2008). There is growing support amongst clinicians and researchers for the routine integration of patient-reported outcomes into cancer clinical practice (Howell et al., 2015; Lipscomb et al. 2007). One patient-reported outcomes that has received a lot of attention in recent years is quality of life (QOL). QOL is the subjective measure of how a person's illness or treatment positively or negatively affects their life (Torrance, 1987). In order to promote positive QOL, health care professionals must pay attention to a patient's physical symptoms as well as their psychosocial and spiritual wellbeing (Bottomley, 2002).

The increasing interest in QOL has led many researchers and clinicians to advocate for the early integration of palliative care (PC) into standard oncology care (Ferrell et al., 2016; Hui & Bruera, 2016; Smith et al., 2012). PC is a type of comfort care that is intended to help patients live well throughout the course of their illness. Because PC is a relatively new and evolving field of medicine, health care professionals have various opinions about what it is, when it should be introduced, and how it can be used to help patients. These different attitudes and perceptions of PC are the subject of this thesis. More specifically, this thesis examines oncologists' perceptions of PC as documented in previous studies and explores how these perceptions might contribute to delays in PC referrals for advanced cancer patients. In Canada, PC services are underutilized and referrals are only made late in the course of disease despite increasing access to PC services and clinical guidelines recommending that referrals be made at the time of diagnosis of an advanced cancer. This thesis, therefore, was developed to better understand the reasons why oncologists are not referring patients to PC as early and as often as is recommended. I hypothesize that this is due, at least in part, by how oncologists perceive PC. Negative attitudes and perceptions toward PC could prevent oncologists from providing early referrals to patients. I hypothesize that these attitudes stem not only from a lack of knowledge on the part of referring oncologists, as is often

suggested in the literature, but also from fundamental differences in the professional cultures of oncology and PC and the distinct professional identities of oncologists and PC physicians.

The objectives of this thesis are: i) to explore oncologists' perceptions of PC services by conducting a systematic review of the current literature; and ii) to critically analyze the existing oncologist-driven models of PC referral from an ethical perspective. This thesis is composed of two manuscripts that, when combined, highlight the problems associated with oncologist-driven models of PC referral. Manuscript 1 consists of a systematic review and narrative synthesis of the current literature investigating oncologists' perceptions and attitudes toward PC. Manuscript 1 highlights the heterogeneity of oncologists' views of PC and the impact that this heterogeneity can have on patient access to PC services. Manuscript 2 situates results of the systematic review within the context of PC gatekeeping by analyzing the ethical issues associated with oncologist-driven models of PC referral. When taken together, these manuscripts act to expand our current understanding of the physician-level barriers to PC referral and provide valuable information about the benefits and risks of oncologist-driven models of PC referral. The findings outlined in this thesis can be used to inform the development of strategies to improve the early delivery of PC for advanced cancer patients and increase inter-professional collaboration between physicians working in oncology and those tasked with providing PC, many of whom are family physicians.

## **Chapter 2 - Literature Review**

### **2.1 Defining palliative care**

Although the meaning of PC has changed throughout the years, the current definition of PC provided by the World Health Organization (WHO) is as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2018).

PC involves the sophisticated coordination of care across health disciplines and can be delivered in a variety of settings such as the patient's home, a hospital, a hospice residence or a long-term care facility (Morrison, 2013). Contrary to popular belief, PC includes but is not limited to end-of-life (EOL) or hospice care. Hospice care is reserved for terminally ill patients with a prognosis of less than 6 months and is usually provided only after all curative treatment has been stopped (Forman, 2003). Unlike hospice care, PC is suitable for anyone suffering from a serious illness regardless of the stage of disease and can be delivered alongside life-prolonging therapies such as surgery, radiation and chemotherapy (WHO, 2018). In the United States, the term *hospice* typically refers to benefit programs and services offered by Medicare or other health insurance providers to terminally ill patients requiring supportive care. Outside of the United States, the term is used to describe the institutions and facilities that provide care to the terminally ill.

According to Von Gunten (2002), there are three distinct levels of PC. *Primary PC* refers to the basic supportive care skills that are required by all physicians. A physician who practices primary PC should be able to, for example, provide basic pain and symptom management as well as initiate routine discussions about disease prognosis and goals of care. *Secondary PC*, however, refers to the consultation services and programs provided by clinicians who are considered to be specialists in the field of PC. *Tertiary PC*, Von Gunten (2002) explains, is a term that is used to describe the PC services provided at academic medical centers where “specialist knowledge for the most complex cases is practiced, researched, and taught”. In countries like Australia and the United Kingdom, it is common for secondary and tertiary PC to be grouped together and referred to as specialty or subspecialty PC. Unlike primary PC, specialty PC is reserved for the advanced and complex cases and is usually delivered by a team of care experts including PC physicians, nurses, psychologists, social workers, physiotherapists and chaplains (Crawford & Price, 2003).

## **2.2 Relevance to family medicine**

In Canada, the distinction between primary and subspecialty PC is less clear. The field of palliative medicine was only granted subspecialty status under the Royal College of Physicians and Surgeons of Canada in 2013, nearly 25 years after it was recognized as a subspecialty in the United Kingdom (Pilkey et al., 2017). For decades, the lack of formal qualifications for palliative medicine in Canada meant that specialist PC clinicians were few in number. As a result, family physicians stepped in to aid in the delivery of secondary and tertiary PC. To meet the educational needs of family physicians and to ensure competence in PC, the College of Family Physicians of Canada began offering an optional year of added competence (YAC) in palliative medicine to family physicians beginning in 1999 (Pilkey et al., 2017). According to the College, the YAC was their way of addressing the shortage of skilled PC clinicians that existed across the country.

A recent survey conducted by the Canadian Society of Palliative Care Physicians (2015) reflects this historical account of palliative medicine in Canada. According to the survey results, family physicians are the most frequent providers of PC in all provinces. Furthermore, the survey found that less than 5% of PC physicians working in Canada consider themselves to be specialists or subspecialists in palliative medicine (CSPCS, 2015). In Canada then, the term “PC physician” is not only used to describe PC specialists but also to describe physicians with a special interest in providing PC, the large majority of whom are family physicians.

In areas where PC specialists are scarce or absent, family physicians are well suited to aid in the provision of specialty PC owing to the similarities in their approach to care delivery, their ability to build rapport with patients and families, and their proximity to the community. Family physicians, like specialist clinicians in palliative medicine, utilize a holistic approach to care that emphasizes the importance of addressing both the physical and psychosocial aspects of illness (College of Family Physicians of Canada, n.d.). It is not uncommon, for example, for a family physician to inquire about how a patient’s symptoms or treatments affect their day-to-day life at work and at home, their personal relationships and their overall happiness and wellbeing. Family physicians are also well suited to deliver PC because they are expert communicators and capable of building strong relationships with patients and families (Shaw et al., 2017). These skills can help family physicians initiate difficult PC-related discussions about prognosis, code status and EOL decisions. Family physicians also use these skills to ensure that the care they provide is patient-centered and context-driven—two values that are central to the practice of PC. One might argue, then, that a family physician who has spent many years building a relationship with a patient and who is well informed about that particular patient’s wants and needs might even be *better* suited than the oncologist or PC specialist to initiate early discussions about PC.



Family physicians also play an important role in the delivery of PC because of their close proximity to the community, particularly in rural areas of the country where PC specialists and comprehensive PC programs are often poor or unavailable. In these communities, family doctors adopt the role of PC providers by default. A study conducted by Ankuda et al. (2017) found, for example, that family physicians who provide PC are more than twice as likely to be located in rural areas. PC specialists and specialty PC teams, on the other hand, tend to be concentrated in urban areas and often work at large hospitals or academic medical centers (CSPCP, 2015; Lynch et al. 2013; Robinson et al., 2009). Recent research has demonstrated, however, that the majority of Canadians would prefer to spend their final months receiving care at home than in a hospital (Tanuseputro et al., 2017; Gomes et al., 2013). Family physicians, with their ability to carry out home visits and deliver care in community settings, are therefore well positioned to provide the type of PC preferred by Canadians.

The recent recognition of palliative medicine as a subspecialty in Canada means that medical residents training in a variety of base disciplines such as internal medicine or pediatrics are now eligible to complete an additional 2 years of training in palliative medicine to become PC specialists (Pilkey et al., 2017). With the first class of PC specialist trainees being enrolled in July 2017, the number of PC specialists is expected to increase in the following years. This does not mean, however, that family physicians will no longer be responsible for delivering PC. As the population of elderly Canadians with complex care needs continues to grow and their life expectancy increases, so too will the need for PC and the need for qualified PC providers. Owing to family physicians' PC skills and proximity to the community, they are well suited to provide support to patients and their family members as well as to help coordinate care with the primary oncology team and other specialists in this new and evolving healthcare climate.

### **2.3 A history of palliative care in oncology**

The origin of PC is deeply rooted in oncology and the two specialities have a joint history that spans over half a century. In the 1950s, when clinicians and scientists had their efforts focused on finding a cure for cancer, patients who could not be saved were often overlooked. According to Clark (2007), it was not uncommon for physicians to abandon terminal cancer patients and send them home when they concluded that nothing more could be done to help them. Patients' physical symptoms, particularly pain, were regarded as inevitable consequences of the disease and often left uncontrolled (Clark, 2007). This neglect of dying cancer patients was reported in several notable studies including a 1952 report published by the Marie Curie Memorial Foundation that detailed the suffering and deprivation of terminal cancer patients living at home. Other works published at the time documented the appalling levels of neglect experienced by patients in nursing homes (Hughes, 1960), described the physical and mental distress of the dying (Hinton, 1963) and identified a link between bereavement and mental illness (Parkes, 1964). By shedding light on the social and clinical aspects of caring for terminal cancer patients, these studies made it alarmingly clear that the provision of care for these patients was inadequate and needed to be improved.

In 1967, English nurse and social worker Dame Cicely Saunders established the world's first modern hospice, St. Christopher's Hospice. The 60-bed facility was located in London and specialized in providing pain relief as well as psychosocial and spiritual support to the terminally ill (Saunders, 1967). While there were a handful of hospices that existed at the time, what made St. Christopher's unique was the emphasis it placed on education and research and its promise to provide care to patients regardless of their social status or religion (Clark, 2007). Before opening St Christopher's, Saunders wrote at length about the need for institutionalized care for advanced

cancer patients. In the following passage, she discusses the shared goals of standard cancer care and hospice care and sets the precedent for hospice care to be viewed as an integral part of whole patient care:

The provision of an institution primarily devoted to what is often called terminal care should not be thought of as a separate and essentially negative part of the attack on cancer. This is not merely the phase of defeat, hard to contemplate and unrewarding to carry out. In many ways its principles are fundamentally the same as those which underlie all the other stages of care and treatment although its rewards are different.

(Saunders, 1964, p. 1)

The opening of St. Christopher's Hospice in 1967 marked the beginning of the modern hospice movement. The movement spread to Canada in the mid-1970s where Dr. Balfour Mount coined the term "palliative care" and founded Canada's first PC center at the Royal Victoria Hospital in Montreal, Quebec (Mount, 1976).

As the hospice movement spread across Europe, Canada and the United States, so too did the traditional notion of PC. PC became synonymous with hospice care and was only considered appropriate for patients who were nearing the end of life. At the time, the WHO described PC as "the active total care of the person whose disease is no longer responsive to curative treatment" (WHO, 1990). PC was, in other words, a type of care provided to those who were dying. In 2002, the WHO amended this definition and replaced it with the current definition which affirms that PC can and should be delivered concurrently with life-prolonging therapy (WHO, 2018). Today, PC is provided to patients suffering from a wide variety of medical conditions. The roots of PC, however, lie in oncology, having developed relatively quickly from an initial mission centered on the care of terminally ill cancer patients.

## 2.4 The benefits of early palliative care

Research has demonstrated that introducing PC early in the course of disease can have significant benefits for advanced cancer patients, their family and the economy. A PC referral is considered ‘early’ if it occurs when a patient’s prognosis is > 6 months or if a patient is referred at the time of diagnosis of an advanced cancer (Zimmerman et al., 2014; Temel et al., 2010; Bakitas et al., 2009). The Canadian Cancer Society (2015) describes an advanced cancer as “a cancer that is unlikely to be cured”. Other terms often used to describe advanced cancer include end-stage, secondary, metastatic or progressive cancer (Canadian Cancer Society, 2015). Even though an advanced cancer can often progress into a terminal illness, death does not have to be imminent or an absolute certainty in these patients. Patients with advanced breast cancer or non-Hodgkin lymphoma, for example, have a 5-year survival rate of 22% and 25%, respectively (Canadian Cancer Society, 2015).

### *Patient benefits*

Although research investigating the effectiveness of PC programs has been conducted for decades, it is difficult to draw conclusions about the benefits of PC from early studies because of the lack of scientific rigor and the diversity of patients, interventions, care settings and treatment targets (Zimmerman et al., 2008). In the last decade, however, researchers have overcome some of these methodological challenges to demonstrate that early PC can improve a variety of patient outcomes such as quality of life, survival, satisfaction with care, symptom burden, psychological distress, communication with providers and mood (Haun et al., 2017; Greer et al., 2013). Since 2008, a total of seven randomized controlled trials (RCTs) evaluating the effectiveness of early PC interventions for patients with advanced cancers have been published (Table 1) (Haun et al., 2017).

**Table 1. Randomized Control Trials investigating the effectiveness of early palliative care.**

Author/year	Study Sample	Methods	Intervention	Outcomes measured
(Bakitas et al., 2009)	N=322 (161 intervention, 161 control)	Parallel-group RCT	Telephone-based palliative care model	Quality of life*, symptom intensity, resource use, mood*, survival, caregiver burden, quality of care
(Bakitas et al., 2015)	N=207 (104 intervention, 103 control)	Parallel-group RCT	Initial in-person consult followed by telephone-based palliative care model	Quality of life, symptom intensity, survival*, resource use, caregiver burden, location of death
(Maltoni et al., 2016)	N=186 (89 intervention, 97 control)	Parallel-group cluster RCT	Regular in-person consults with palliative care team	Quality of life*, mood, family satisfaction, aggressiveness of care
(McCorkle et al., 2015)	N=146 (66 intervention, 80 control)	Parallel-group cluster RCT	Regular phone and in-person contact with palliative care team	Quality of life, symptom distress, health distress, emotional distress, functional status, self-rated health, anxiety, self-efficacy*, uncertainty*
(Tattersall et al., 2014)	N=120 (60 intervention, 60 control)	Parallel-group RCT	Initial in-person consult with follow-ups at patients' discretion	Quality of life, symptom severity, perceived support, resource use, place of death
(Temel et al., 2010)	N=151 (77 intervention, 74 controls)	Parallel-group RCT	Initial in-person consult with follow-ups at patients' discretion	Quality of life*, mood*, resource use*, aggressiveness of care*, resuscitation preferences*, survival*
(Zimmerman et al., 2014)	N=461 (228 intervention, 233 control)	Parallel-group cluster RCT	Varied inpatient and outpatient palliative care delivery models	Quality of life*, symptom intensity*, medical interaction, satisfaction with care*

\* Outcomes reported as significantly improved in the PC intervention group

Among these RCTs is a widely cited study by Temel et al. (2010). In order to investigate the effectiveness of early PC on patient outcomes, Temel and colleagues recruited 151 patients newly diagnosed with metastatic non-small-cell lung cancer and assigned half of them to receive early PC in addition to standard oncology care. All initial PC consults were provided less than 8 weeks after diagnosis. Three months after the intervention began, the early PC group showed marked improvements in quality of life, exhibited fewer depressive symptoms and received less

aggressive treatments near the end of life. Most surprisingly, Temel et al. (2010) discovered that patients in the early PC group survived an average of 2.7 months longer than patients receiving standard care alone. Positive impacts on patient survival have also been reported by Bakitas et al. (2015). In their study, 207 patients with advanced cancer were assigned to receive an early PC intervention starting either immediately following study enrollment or after a 3-month delay. The survival rates for patients in these two groups were 63% and 48%, respectively. Although these findings are noteworthy, more research is needed to confirm the effects of early PC programs on survival and determine the exact mechanism by which early PC leads to increases in survival.

#### *Caregiver benefits*

The benefits of early PC are not limited to advanced cancer patients; caregivers and family members have been shown to benefit from PC services as well. Research demonstrates that, when compared to patients receiving standard care alone, caregivers of patients receiving early PC in addition to standard cancer care have improved psychosocial well being (Sun et al., 2015), increased satisfaction with care (McDonald et al., 2016) and exhibit fewer depressive symptoms (Dionne-Odom et al., 2015). Although the majority of the observed benefits are the result of PC interventions targeting the caregivers directly, El-Jawahri et al. (2016) found that caregivers can also benefit from PC indirectly through improvements in patient outcomes. In their study, family caregivers of patients receiving early PC reported lower depression symptoms and increased QOL despite the fact that they did not receive targeted interventions themselves and were not required to attend PC appointments with patients. According to El-Jawahri et al. (2016), these results suggest that early PC generates a positive feedback loop whereby caregivers are positively impacted by patient outcomes, thereby making it easier for caregivers to provide support to their loved ones and improve patient outcomes themselves.

### *Economic benefits*

In addition to having positive impacts on cancer patients and family caregivers, early PC has been shown to decrease the use of hospital resources and result in significant cost savings (Smith et al., 2014). Compared to patients receiving standard care alone, PC patients have fewer hospitalizations, ICU admissions, hospital readmissions and visits to the ER, particularly in the last months of life (Triplett et al., 2017; Scibetta et al., 2016; Gade et al., 2008). Cost savings vary, with studies reporting that patients receiving PC cost 9-25% less than patients receiving standard care alone (May et al., 2015). Research has also demonstrated that earlier PC consults can lead to greater cost savings. May et al. (2015) found that advanced cancer patients receiving a PC consult 6 days and 2 days after hospital admission had cost savings of \$1,312 and \$2,280, respectively. It is hypothesized that these cost savings stem from improved communication about goals of care and treatment options, allowing patients to make informed decisions to avoid costly futile treatments (May et al., 2015).

### *Negative findings*

Although the evidence supporting the effectiveness of early PC programs is convincing, the literature does not unanimously support early PC. Tattersall et al. (2014), for example, found that early contact with a PC nurse did not lead to a significant reduction in patient symptoms or improve QOL. Similarly, Bakitas et al. (2015) did not observe differences between the control and intervention groups in patient-reported outcomes such as QOL and mood, despite finding an increased 1-year survival rate for patients in the PC group (63%) compared to the control group (48%). These results contradicted their previous trial of the ENABLE (Educate, Nurture, Advise Before Life Ends) project where they found that patients receiving early PC had higher scores for QOL and mood (Bakitas et al., 2009).

These negative findings can be attributed, however, to methodological factors such as the intensity of PC exposure and the length of the PC intervention. In the article by Tattersall et al. (2014), for example, the authors acknowledge that their negative results might be due to the low ‘dose’ of PC contact experienced by participants. They used an intervention that relied on sparse contact with a PC nurse instead of regular contact with a PC team or PC physician like the RCTs by Zimmerman et al. (2014) and Temel et al. (2010). In the article by Bakistas et al. (2015), the authors explain that their negative findings could be linked to the short 3-month duration of their intervention. This hypothesis aligns with findings by Zimmerman et al. (2014) which show that the effects of PC interventions on patient-reported outcomes are typically not visible until four months after PC has been implemented. Furthermore, Bakistas et al. (2015) acknowledge that the control group used in their study had been contaminated. The authors explain that nearly half of the participants in their standard care group were referred to PC earlier than the researchers had anticipated at the request of the primary oncologist.

## **2.5 Clinical practice guidelines for palliative care**

The increasing evidence supporting the early integration of PC into standard cancer care has led many large healthcare organizations to adjust their PC guidelines in accordance with the new findings. The National Comprehensive Cancer Network (NCCN), the American Society of Clinical Oncology (ASCO), the European Society of Medical Oncology (ESMO) and the World Health Organization (WHO) are just a few of the organizations that have made changes to their PC guidelines in recent years. They now recommend that physicians refer patients to PC early in the course of disease, ideally at the time of diagnosis of advanced cancer. The NCCN guidelines, for example, state that:



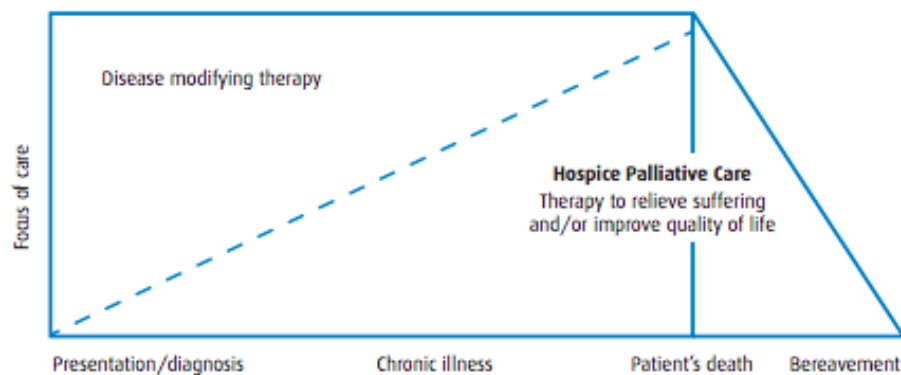
Palliative care begins at diagnosis and should be delivered concurrently with disease-directed, life-prolonging therapies [...] and become the main focus of care when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired. (Levy et al., 2012, p. 1300)

According to the ASCO, a consult with an interdisciplinary PC team is optimal and should occur within 8 weeks of diagnosis (Ferrell et al., 2016). The ASCO also suggests that PC consults be made available to family members as well as patients, and that PC services be offered in both inpatient and outpatient settings. The primary oncology team should be assessing the PC needs of patients regularly and referring them promptly if they see that the patient has a high symptom burden (Ferrell et al., 2016; Levy et al., 2009). Importantly, the guidelines mention that patients and their families should be educated on PC and that PC should be described as an integral part of ongoing cancer care rather than care reserved for the terminally ill (Levy et al., 2009).

## **2.6 Models of early palliative care**

### *Canadian Hospice and Palliative Care Association model*

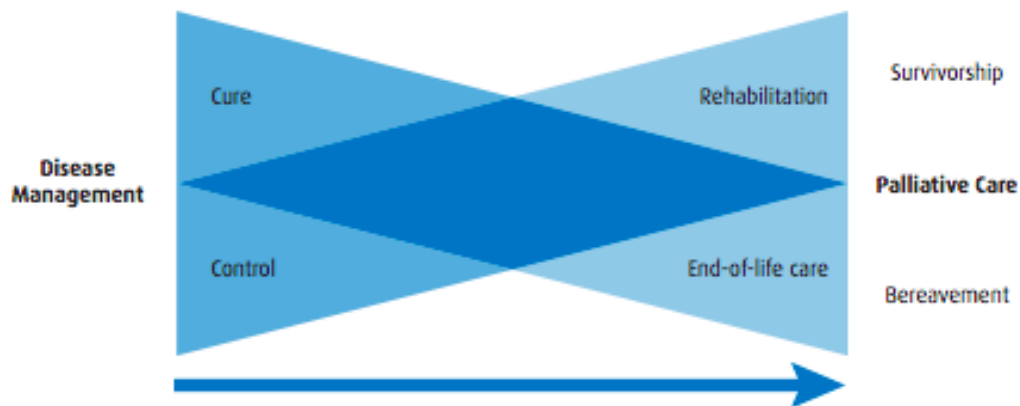
Changes in the clinical practice guidelines were followed by the development of new integrated models of early PC delivery. The Canadian Hospice and Palliative Care Association ([CHPCA], 2013) put forth a model which recommends that PC be made available to patients during the entire course of their disease, from diagnosis until death and then into bereavement (Figure 1a). As a patient progresses through the stages of their illness, PC plays an increasingly significant role. The focus at the beginning of the illness trajectory is primarily on curative treatment with minimal involvement from the PC team. As a patient approaches death, disease-modifying therapy decreases and the focus shifts towards PC and bereavement support for family members and friends.



**Figure 1a. CHPCA model of palliative care (CCS, 2016).**

### *The bow-tie model of palliative care*

Although the CHPCA model successfully accounts for the integration of PC into standard oncology care, it omits patients who survive their cancer. The bow-tie model of PC (Figure 1b) adds to the CHPCA model by addressing survivorship in addition to bereavement. Developed by Pippa Hawley (2014), the bow-tie model of PC is depicted as two overlapping triangles, the first representing PC and the other representing disease-modifying therapies. PC is introduced when a patient is diagnosed with cancer and it increases as the disease progresses. Curative treatment, on the other hand, decreases throughout the illness trajectory as a patient either enters remission or approaches death. As treatment slows, members of the PC team can help by providing EOL care or by assisting with rehabilitation and reintegration into society should the cancer therapy prove to be effective. One of the distinguishing strengths of the bow-tie model, aside from the inclusion of survivorship, is the fact that the overlapping triangles symbolize a partnership between the PC and oncology teams. It is a visual representation that oncology and PC should be delivered not only concurrently, but collaboratively, as the primary oncology team works with the PC team to ensure that advanced cancer patients and their family members receive the best possible care.



**Figure 1b. Bow-tie model of palliative care (CCS, 2016).**

## **2.7 Barriers to early palliative care referral**

Despite the new evidence-based guidelines and recommendations for integrated models of oncology and PC, cancer patients continue to receive PC only in the late stages of disease, and some patients never receive it at all (Scibetta et al., 2016; Hui et al., 2014; Hui et al., 2012; Osta et al., 2008). While conducting a chart review of 922 American cancer decedents, Scibetta et al. (2016) found that only 32.2% of patients ever received a PC referral. Of the patients who do get referred, only one-third are referred ‘early’ (Scibetta et al., 2016; Hui et al., 2014). Even at the M.D. Anderson Cancer Center in Texas, which is often regarded as one of the best cancer centers in the world, the median time between a patient’s first PC consult and death is reported to be a mere 1.4 months (Hui et al., 2012).

In Canada, PC referral practices are less well understood and estimates about the timing of PC referrals have not been documented. In one recent chart review of cancer decedents at the Cancer Center of Southeastern Ontario, researchers found that only 42% of patients had received a PC consult (Raskin et al., 2016). Another chart review, conducted by the Canadian Institute for Health Information (2015), contained data on the PC designations or “codes” of cancer patients

who died in acute-care hospitals across the country. The data showed that although 86.5% of patients were labeled as requiring PC, over three-quarters of them were only labelled during their final hospital admission. Furthermore, the PC codes did not provide any information about the range or scope of PC services actually received by patients before they died. It is possible that only a small fraction of patients with a PC code actually received a PC consult. Accurate data about the frequency and timing of PC referrals is needed to better understand the extent of PC underutilization in Canada.

Over the last decade, researchers have attempted to identify the barriers to PC referral for advanced cancer patients with the goal of developing programs and interventions to improve the delivery of early PC. An overview of these PC barriers has been provided in a number of review articles (Love & Liversage, 2014; Aldridge et al., 2016; Ahmed et al., 2004). The PC barriers described in the literature fall into three main categories: 1) system-level barriers, 2) physician-level barriers and 3) patient-level barriers. Although this thesis focuses primarily on physician-level barriers to early PC referral, all three categories of barriers must be addressed to ensure that advanced cancer patients received appropriate access to PC services.

### *System-level barriers*

Researchers like Aldridge et al. (2016) argue that the lack of early referrals to PC is due primarily to difficulties in accessing care services and a small PC workforce. Problems with PC accessibility are common in the United States, where only 67% of hospitals with 50 beds or more have established PC programs (Dumanovsky et al., 2016). In large hospitals with more than 300 beds, however, access to PC is almost universal (Dumanovsky et al., 2016). The small size of the PC workforce is often to blame for the lack widespread access to PC services. Although there are more than 6,700 board-certified PC physicians currently working in the United States (American

Academy of Hospice and Palliative Medicine, 2017), this is significantly less than the estimated 18,000 PC physicians required to meet the increasing demand for PC (Lupu & Force, 2010).

Further complicating matters in the United States is the Medicare Hospice Benefit (MHB), which essentially makes patients choose between disease-modifying therapy and PC. The MHB is a healthcare reimbursement option that covers comfort care for patients who have chosen to forgo curative treatment. Once a patient signs up to receive the MHB, Medicare will no longer pay for any treatments intended to control their disease (Centers for Medicare and Medicaid Services, 2017). An official government booklet that provides information for patients about the MHB states the following:

When you start hospice care, you've decided that you no longer want care to cure your terminal illness and related conditions, and/or your doctor has determined that efforts to cure your illness aren't working. Medicare won't cover [treatment intended to cure your terminal illness and/or related conditions] once your hospice benefit starts. (Centers for Medicare and Medicaid Services, 2017)

For patients who cannot pay out-of-pocket for their care, the MHB puts them in a position that forces them to choose between PC and cancer treatment. This type of system-level barrier is unrelated to the availability of PC services. A patient on Medicare might very well have PC services available to them, but their oncologist might never write them a referral because the patient cannot afford the services and the government will not cover the costs.

Less is known about the system-level barriers of PC in Canada. The often-cited statistic is that only 16-30% of Canadians currently have access to or receive PC (Canadian Hospice and Palliative Association, 2014). According to Downie & Lloyd-Smith (2014), however, there are a number of problems with this estimate. First, the estimate is based on outdated data collected by

the Canadian Institute for Health Information (2007) from 2003 to 2004. Access to PC has likely improved since then, due to significant increases in funding for PC research, new PC initiatives and expanded PC education for healthcare professionals (Carstairs, 2010). Second, the estimate only accounts for patients who received PC in acute-care hospital settings and ignores the subset of the population who receive PC in the community, in a hospice residence, or at home (Hannon et al., 2015). Nevertheless, it can be assumed that access to PC services in Canada is still lacking. In order to determine if access to PC is acting as a significant barrier to PC referral, however, we need a reliable and comprehensive assessment of the country's access to and utilization of PC.

#### *Physician-level barriers*

Many authors also list the referral practices of physicians as a significant barrier to the use of early PC services (Aldridge et al., 2016; Kain & Eisenhauer, 2016; Leblanc et al., 2015; Von Roenn et al., 2013; Bruera & Hui, 2010; Malin, 2004). The results of a survey by Wentlandt et al. (2012) found that only one-third of Canadian oncologists refer patients to PC at the time of diagnosis despite 94% claiming that they have access to PC services. Buckley de Meritens et al. (2017) reported similar results in the United States, with only 30% of the 145 participating oncologists reporting that they would refer cancer patients to PC at first recurrence despite the fact that 92% have PC services available at their hospital. Similar trends in referral practices were observed in Europe (Charalambous et al., 2014) and Australia (Ward et al., 2009). Overall, what these studies demonstrate is that oncologists are reluctant to refer patients to PC even if they have access to PC services. Guaranteeing the availability of PC services is therefore not a sufficient way to ensure that advanced cancer patients receive a timely referral to PC. This evidence suggests that the referral practices of oncologists, rather than issues in PC accessibility, are the driving force behind the lack of early PC referrals for advanced cancer patients.

There are a variety of reasons why oncologists might not to refer a patient to PC. These reasons include a fear that patients and families will feel abandoned (Buckley de Meritens et al., 2017; Charalambous et al., 2014; Le et al., 2014; Kierner et al., 2010), discomfort talking about PC with patients (Hui et al., 2016; Johnson et al., 2008), a belief that PC services are not needed (Morikawa et al., 2016; Johnson et al., 2008; Cherny and Catane, 2003) and the misconception of PC as end-of-life care (Schenker et al., 2014; Bakitas et al., 2013). Many of these physician-level barriers are thought to stem from a lack of PC knowledge and training on the part of the referring oncologists. Mandatory PC rotations for oncology fellows are incredibly uncommon, especially in the United States (Hui et al., 2010). Eskander et al. (2014), for example, found that only 11% of the gynecologic oncology fellows they surveyed had completed a PC rotation during their fellowship. Without proper training in PC, referring physicians might not be able to understand and appreciate the full range of services that PC can offer to patients or the appropriate timing for PC referral.

#### *Patient-level barriers*

Oncologists also list patients' negative attitudes towards PC services as a major barrier to referral (Charalambous et al., 2014; Wentlandt et al., 2012; Ward et al., 2009). According to Hawley (2017), there are a variety of reasons why patients and their family members might be reluctant to accept a PC referral from a healthcare professional. Patients who associate PC with "where people go to die" might choose to decline a PC referral in order to avoid talking about death or as a means to try and avoid death altogether (Hawley, 2017). Patients might fear that accepting a referral to PC means that their treatment will stop or that they will be seen as giving up (Hawley, 2017). Patients might also worry that introducing a new care team will weaken their relationship with the primary oncology team (Hawley, 2017).

Although these reasons are personal in nature, they generally stem from a lack of patient and family knowledge about the scope and benefits of PC. Patients and their caregivers tend to have attitudes and perceptions about PC that are associated with death, EOL, hopelessness and dependency (Zimmerman et al., 2016; Collins et al., 2017). There is a stigma associated with the word “palliative” that provokes avoidance in patients and caregivers (Zimmerman et al., 2016). To address this stigma, researchers have proposed changing the name from “palliative care” to “supportive care” (Fadul et al., 2009; Dalal et al., 2011). Although this name change is reported to increase the number of inpatient PC referrals and promote earlier outpatient referrals to PC (Dalal et al., 2011), some studies have demonstrated that a name change would have little or no effect on physicians’ referral practices (Rhondali et al., 2013; Zimmerman et al., 2016; Masciaz et al., 2013; Milne et al., 2013). Other researchers argue that PC needs a complete rebranding, which would include changing the name, disseminating positive messages about PC services and delivering a high-quality PC experience to patients (Zimmerman et al., 2016; Berry et al., 2016).

## **2.8 Summary**

The current literature suggests that integrating PC early alongside standard cancer care can positively impact patient outcomes such as QOL and survival, significantly improve the wellbeing of family caregivers and result in substantial resource and cost savings. This evidence has led many large healthcare organization to change their clinical practice guidelines in support of concurrent models of oncology and PC. More research is needed, however, to corroborate the effectiveness of early PC in light of negative findings. According to Haun et al. (2017), more research is on the way. They identified 20 ongoing studies and 10 studies awaiting assessment, all of which investigate the effectiveness of early PC. This new evidence will likely contribute to clarifying the specific effects of PC interventions on patient, family and economic outcomes.



Early PC is an emerging field that has been shown to significantly improve the health and wellbeing of advanced cancer patients and their families. Unfortunately, there are a number of barriers in place that prevent cancer patients from receiving a timely referral to PC services. In rural areas, for example, accessing PC can be a challenge due to the low availability of local PC services and staff. Studies have shown, however, that low rates of PC referral also exist in urban areas where PC access is almost universal. This research suggests that accessibility is likely not the driving force behind the late referral practices of many oncologists working in countries with a high level of PC integration. Rather, PC access appears to be part of a much larger problem of PC underutilization that is also caused by patient and physician-level factors.

This finding is important because the majority of PC initiatives currently underway or in development are targeting issues related to PC accessibility instead of addressing issues related to the referral practices of oncologists. In Canada, for example, a private members bill proposing a national framework for universal access to PC was granted a Royal Assent and made an Act on December 12, 2017 (*Framework on Palliative Care in Canada Act*, 2017). The Act stipulates the need for increased PC training, a larger PC workforce and increased research on that state of PC in Canada (Vogel, 2017). This Act is a step in the right direction because increasing access to PC is necessary and important, however, the impact of the Act on clinical practice will be limited if the PC services are not used. If we want these kinds of initiatives to have an impact, we need to understand why oncologists are not providing referrals to PC and encourage them to do so.

As the gatekeepers of PC for advanced cancer patients, oncologists can offer a wealth of insight into why some patients are referred to PC while others are not. Speaking to oncologists can reveal information about what they think about PC and how they feel about collaborating with PC physicians. Although numerous studies have investigated oncologists' perceptions of

PC, no study has attempted to synthesize these findings and make sense of the overarching themes emerging from the results. The fields of oncology and PC have different origins and emphasize different values. Whereas PC focuses on managing the physical and psychosocial needs of patients and their families, oncology focuses more on the diseases themselves. PC providers value the quality of life over the prolongation of life, and the same cannot be said for most specialists in oncology. It follows then, that the professionals who work in these two fields might have different perceptions and attitudes about what it means to provide quality care to advanced cancer patients.

Previous research has demonstrated that only one-third of oncologists provide early PC referrals to advanced cancer patients despite having access to PC services (Buckley de Meritens et al., 2017; Charalambous et al., 2014; Wentlandt et al., 2012; Ward et al., 2009). In order to understand what is driving these late referral practices, I conducted a systematic mixed studies review of the current literature investigating oncologists' perceptions and attitudes toward PC for advanced cancer patients. Currently, no review articles exist discussing physician perceptions of PC despite the growing amount of research in this area. Reviewing oncologists' perceptions of PC is important for two reasons. First, as the gatekeepers to PC, oncologists can offer insight into why patients are or are not receiving referrals to PC. Second, understanding the physician-level barriers to early PC referral is crucial to inform the development and implementation of future strategies to improve the provision of PC for advanced cancer patients. This thesis also engages in a critical analysis the ethical issues associated with oncologist-driven modes of PC referral to further support and advocate for interventions targeting the referring oncologists. The findings contained in the following chapters attempt to bridge the gap between the current evidenced-based recommendations for early PC and the late referral practices of oncologists.

## **2.9 Research Questions**

This thesis addresses the following research questions:

Manuscript 1: What are oncologists' perceptions and attitudes toward PC and the barriers and facilitators to early PC referral?

Manuscript 2: What are the ethical issues associated with oncologist-driven models of PC referral?

### **Chapter 3 - Manuscript I:**

A systematic mixed studies review and narrative synthesis of oncologists' perceptions and attitudes towards palliative care for advanced cancer patients

#### **Abstract**

**Background:** Despite the progress that has been made in the fight against cancer, the number of individuals diagnosed with the disease continues to rise. In order to improve the quality of life of patients and families dealing with the physical and psychosocial impacts of a cancer diagnosis, researchers have advocated for the early implementation of palliative care services. The majority of patients, however, are only referred to palliative care in the last few weeks of life. **Objectives:** The aim of this manuscript is to explore oncologists' perceptions and attitudes toward palliative care in order to better understand why they are not referring patients as early as is recommended. **Methods:** A systematic mixed studies review and narrative synthesis was undertaken to review the existing literature investigating oncologists' perceptions and attitudes toward palliative care for advanced cancer patients. **Results:** A total of 21 articles met the inclusion criteria. The main themes identified from the literature include: 1) the value of palliative care, 2) the timing of palliative care referral, 3) the role of the palliative care provider, 4) the coordination of care, 5) the philosophy of care and 6) the impact of palliative care referral on the patient. **Conclusions:** Oncologists' perceptions of palliative care are derived from a combination of knowledge factors

and identify factors. A lack of provider knowledge about the scope and timing of palliative care referral and an underlying conflict between the professional cultures of oncology and palliative care can both contribute to the late referral practices in oncology. These findings can be used to inform the development of new policies and programs aimed at increasing collaboration between oncology and palliative care teams to ultimately improve the early delivery of palliative care.

### **3.1 Introduction**

According to the Canadian Cancer Society (2017), one in every two Canadians will be diagnosed with cancer in their lifetime. Cancer is the country's leading cause of death, with approximately 80,000 Canadians dying every year from the disease (Canadian Cancer Society, 2017). In addition to the debilitating physical symptoms, a cancer diagnosis can have significant psychosocial impacts on the patient, their family members and the community (Holland, 2010; Page & Adler, 2008). Palliative care (PC) is an approach to care that can help manage these side effects and improve the overall quality of life for cancer patients and caregivers (World Health Organization, 2018). When introduced early, usually at a prognosis of greater than 6 months, PC has been shown to improve patient and caregiver outcomes such as symptom intensity, mood and satisfaction with care (Maltoni et al., 2016; McDonald et al., 2016; Zimmerman et al., 2014; Temel et al., 2010; Bakitas et al. 2009). Two studies have even found that early PC interventions can lead to significant improvements in patient survival (Bakitas et al., 2015; Temel et al., 2010). In addition to patient and caregiver benefits, early PC has been shown to lower healthcare costs by reducing the number of futile treatments delivered to patients' nearing the end of life (May et al., 2015; Hui et al., 2014).

In response to this new evidence, the American Society of Clinical Oncology (ASCO) and other large healthcare organizations now recommend that cancer patients be referred to PC

early, ideally within 8 weeks of a diagnosis of advanced cancer (Ferrell et al., 2016; Levy et al., 2009). Studies show, however, that the majority of cancer patients only receive their first PC consult in the final weeks of life (Scibetta et al., 2016; Hui et al., 2014; Hui et al., 2012; Osta et al., 2008). Hui et al. (2012) found, for example, that patients being treated at the University of Texas M.D. Anderson Cancer Center had their first PC consult a median of 1.4 months before they died. In Canada, less is known about the frequency and timing of PC referrals. One recent chart review of cancer decedents at the Cancer Center of Southeastern Ontario, however, found that only 41% of decedents had received a PC consult (Raskin et al., 2016).

In the existing literature, delays in PC referral are attributed to a combination of factors, including a lack of access to PC services (Aldridge et al., 2016), patient and family reluctance to discuss early PC (Zimmerman et al., 2016), and provider misconceptions about the benefits and scope of PC services (LeBlanc et al., 2015; Bakitas et al., 2013). Most new PC interventions and policies, however, are focused on addressing the system-level barriers to referral rather than the patient- or physician-level factors. Researchers and policy makers are concerned with enhancing the PC workforce, increasing the availability of PC services and investing in PC research (Vogel, 2017; Meier, 2011). Although these initiatives are important, studies have demonstrated that PC underutilization is more than just a problem of PC accessibility. Oncologists are reluctant to refer patients to PC even when they acknowledge the availability of PC services (Buckley de Meritens et al., 2017; Charalambous et al., 2014; Wentlandt et al., 2012; Ward et al., 2009). Therefore, to improve the early provision of PC for advanced cancer patients, the barriers existing at the level of the referring oncologists also need to be addressed.

Although previous studies have explored oncologists' perceptions of PC and the barriers and facilitators to PC referral, no review article has attempted to summarize their views in order

to better understand why they are not referring patients to PC as early and as frequently as they should. This manuscript aims to address this knowledge gap by exploring the perceptions and attitudes of oncologists toward PC as they are documented in the existing literature. The goal of this systematic review will be to shed light on the physician-level barriers to early PC in order to inform the development of new strategies to increase inter-professional collaboration between oncologists and PC physicians to ultimately improve the early delivery of PC to cancer patients.

## **3.2 Methods**

### **3.2.1 Methodology**

A systematic Mixed Studies Review (MSR) was chosen to examine oncologists' attitudes and perceptions of PC. Although qualitative methods are best suited for investigating perceptions of care, the literature about oncologists' perceptions and attitudes toward PC contains a number of quantitative survey studies. This review, therefore, required a methodology appropriate for synthesizing quantitative and qualitative data. According to Pluye et al. (2009), the MSR is a type of literature review "that concomitantly examines qualitative, quantitative and mixed methods primary studies", making it suitable for the objectives of this thesis. The purpose of an MSR is to expand our understanding of a certain topic by synthesizing the knowledge obtained from a variety of different types of empirical research. It can be exploratory or confirmatory in nature and usually involves an iterative process whereby researchers integrate quantitative and qualitative results by moving back and forth between the two types of data (Pluye et al., 2009).

### **3.2.2 Database search**

Relevant literature for inclusion in this MSR was retrieved from an initial online database search in Medline and EMBASE. The search was limited to English articles published between January 2003 and November 2017. January 2003 was chosen as the lower limit for the date range

to ensure that the resulting articles used the contemporary definition of PC established by the WHO in late 2002. The search included the following terms: ('palliative care' OR 'supportive care') AND ('oncolog\*' or 'cancer') AND ('perception\*' OR 'percieve\*' OR 'perspective\*' OR 'attitud\*' OR 'opinion\*' OR 'prefer\*'). Since this review emphasizes oncologists' utilization of early PC, which is typically introduced at a prognosis of >6 months, search terms related to end-of-life or hospice care were not used. Relevant articles were also obtained through a snowballing technique by examining the reference lists of review articles and selected studies. No restrictions were placed on study methodology. The results were imported into the reference management software EndNote so that the references could be organized and the duplicates could be removed.

### **3.2.3 Selection criteria**

The articles obtained from the initial database search were first screened by title and then by abstract. The resulting articles were subject to a full text review and omitted if they did not meet the selection criteria. Selected articles consisted of original research conducted in countries where PC services are considered to be at a stage of advanced integration. According to the categorization of palliative care development established by the Worldwide Palliative Care Alliance (WPCA), countries with an advanced integration of PC are classified into Group 4b (WHO, 2014). Group 4b countries include: Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom and the United States of America. Group 4b countries are described by the WPCA as having the following characteristics (WHO, 2014):

- The development of a critical mass of palliative care activism in a wide range of locations
- Comprehensive provision of all types of palliative care by multiple service providers



- Broad awareness of palliative care on the part of health professionals, local communities and society in general
- Unrestricted availability of morphine and all other strong pain-relieving medicines
- Substantial impact of palliative care upon policy, in particular upon public health policy
- The development of recognised education centres
- Academic links forged with universities
- The existence of a national palliative care association.

Countries with a lower level of PC integration were excluded to control for issues of PC access.

This review is being conducted to better understand why oncologists are not providing early referrals to PC *despite* having access to PC services. It is important, then, that oncologists who participate in the selected studies have a basic knowledge of PC and good access to PC services.

Studies were excluded if they did not examine the attitudes or perceptions of oncologists or oncology fellows. This means that articles investigating the perceptions or attitudes of medical residents, patients, caregivers, nurses or other allied health professionals were omitted. If a study examined the views of oncologists as well as the views of other health professionals, then it was only included if the data collected from oncologists was analyzed and reported separately. This was the case for the articles by Fadul et al. (2009), Hui et al. (2015) and Peretti-Watel et al. (2004). Exceptions were also made for studies in which the participants were cancer specialists but not specifically oncologists. Johnson et al. (2011), for example, interviewed respiratory physicians and colorectal surgeons in addition to oncologists. They justified the inclusion of these physicians in their study because a large fraction of their patient population is reported to be cancer patients. For simplicity, participating physicians from all of the selected studies will be referred to as “oncologists” in this thesis even though this might not be their official title.

The selected articles investigated multiple topics related to oncologists' perceptions and attitudes towards PC. These topics include oncologists' understanding of the definition of PC, their knowledge about the benefits of PC for cancer patients, and their views on the optimal timing for PC referral. Studies were also included if they sought to determine oncologists' views about the barriers to and facilitators of early PC referral. If an article did not discuss perceptions, attitudes or any other related concept, then it was excluded from the review.

### **3.2.4 Quality appraisal**

Following the full-text review, the quality of the selected articles was assessed using a MSR scoring system developed by Pluye et al. (2009). The scoring system addresses a number of methodological quality criteria including the study objectives, sampling strategy, methods, context and analysis. Pluye et al. (2009) organize a total of 15 quality criteria into four groups of study components: 1) qualitative, 2) quantitative experimental, 3) quantitative observational, and 4) mixed methods. A 'quality score' was calculated for each article based on the type of quality criteria relevant to the design of each study. A qualitative descriptive study using semi-structured interviews, for example, is scored using the 6 quality criteria in the qualitative group. The quality scores for each article are listed alongside the descriptive information in Table 3.

### **3.2.5 Data synthesis**

After the articles were selected and appraised for quality, the results of the studies were synthesized using the narrative synthesis approach outlined by Popay et al. (2006). Popay et al. (2006) describe narrative synthesis as an approach "that relies primarily on the use of words and text to summarize and explain the findings of the synthesis". The goal of narrative synthesis is to tell a story about a particular real-life phenomenon. Although Popay et al. (2016) summarize the steps of narrative synthesis in reference to the effectiveness of a particular intervention, they also

specify that a narrative synthesis approach can be used to address a wide range of research questions. Two of the most commonly cited weaknesses of narrative synthesis are its lack of transparency (Dixon-Woods et al., 2005) and the lack of formal guidance about how to conduct this form of synthesis (Mays et al., 2005). The guide written by Popay et al. (2006), however, has helped to tackle these methodological weaknesses by suggesting specific techniques and tools to help enhance the transparency and clarity of narrative synthesis.

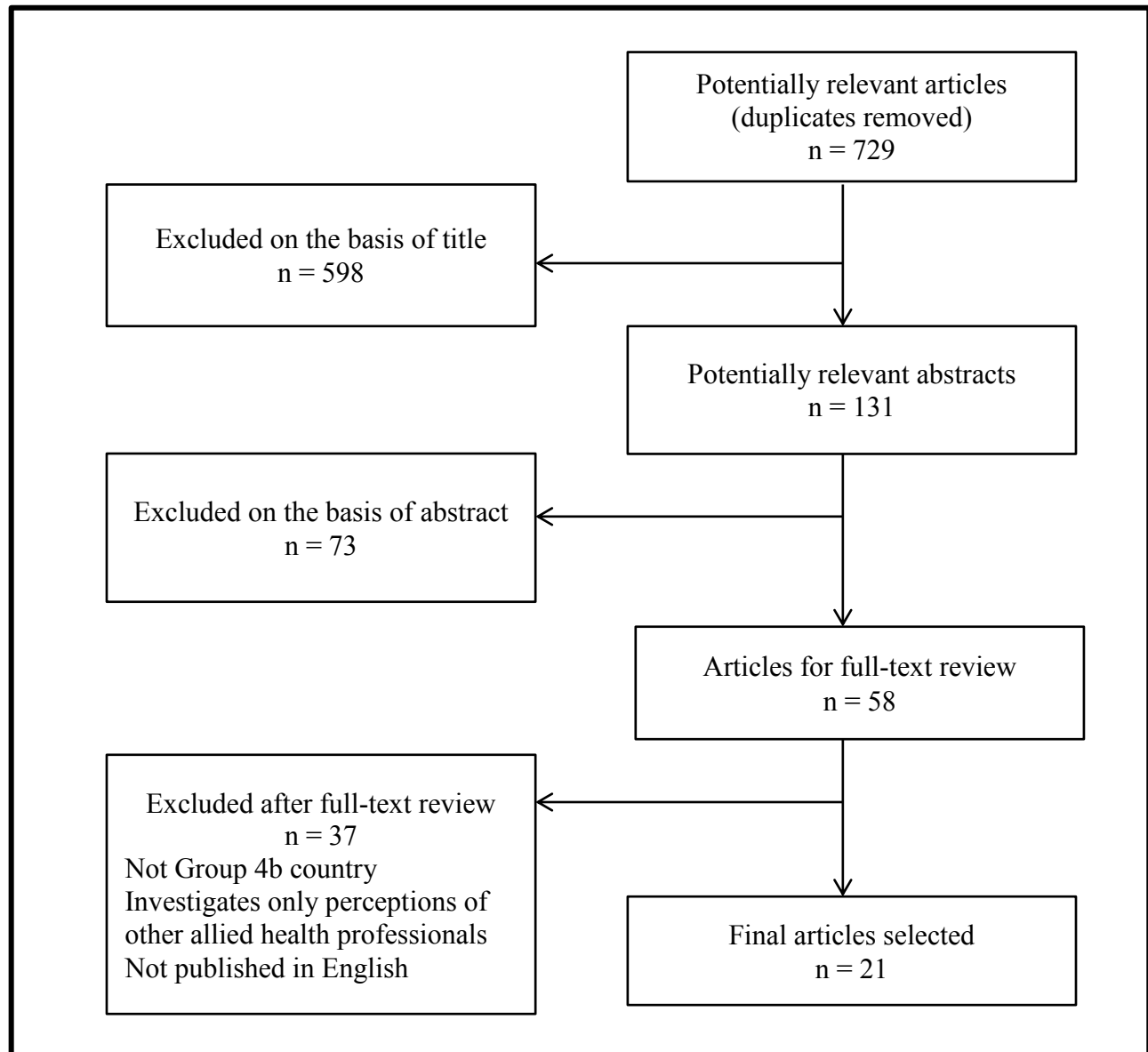
As a first step in the synthesis process, the empirical data from the results section of each selected article was extracted if it was relevant to the research question. The interpretations of the results, described in the discussion section of each article, were not included in the synthesis. A complementary stance was then used to integrate the quantitative and qualitative results from the selected studies. A complementary stance is adopted when the quantitative and qualitative data contribute to one another but are treated separately (Pluye et al., 2009). In other words, the qualitative results are not transformed into quantitative findings, or vice-versa. For quantitative survey studies, answers to questions referencing perceptions or attitudes of PC were extracted and summarized as percentages in an Excel spreadsheet. In cases where two or more studies asked respondents the same question, a range of percentages was created from the data. For the qualitative studies, themes relating to oncologists' perceptions of PC were extracted. Thematic analysis was then used to identify the most recurrent and important themes across the different types of studies. These themes represent a summary of the current knowledge about oncologists' perceptions of PC and the barriers and facilitators to early PC referral. The relationship between these themes was explored in the discussion section in order to gain a better understanding how oncologists perceive PC and why they are reluctant to refer patients to PC as often and as early as is recommended.

### **3.3 Results**

#### **3.3.1 Description of included studies**

The results of the literature search are summarized in Figure 2. A total of 729 articles were retrieved from the initial database search, excluding duplicates. Each article was screened by title and excluded if the title clearly indicated that the study did not meet inclusion criteria. A number of titles, for example, specified that the study examined nurses' or patients' perceptions of PC and not the perceptions of oncologists. The title screening yielded 131 studies for abstract review, after which only 58 studies remained. These 58 articles were subject to a full-text review. During this stage, articles were excluded if they examined oncologists' perceptions of certain facets of PC, like palliative sedation or end-of-life conversations, but did not examine PC more broadly. Articles were also excluded if the full-text article was published in a language other than English or if the perceptions of oncologists could not be isolated from those of other allied health professionals. Given the exploratory nature of this thesis and the limited amount of research on the topic of PC perceptions, none of the articles were excluded based on their quality appraisal score alone. The full-text screening also ensured that the selected studies were conducted in a country with an advanced level of PC integration. An exception was made for the study by Cherny and Catane (2003), whose participants were all members of the European Society of Medical Oncology but practiced in a variety of countries which were not specified in the article.

Following the full-text screening, 21 articles were selected for inclusion in this review. Eight of the articles used qualitative methods, twelve used quantitative survey methods and one used mixed methods. Most of the selected studies were conducted in the United States (n=9) or Australia (n=4), with the remaining studies taking place in Canada (n=2) or various countries in Europe (n=6). Additional descriptive characteristics of the studies are summarized in Table 3.



**Figure 2. Flowchart of Medline and EMBASE database search.**

### 3.3.2 Thematic analysis of selected literature

Six themes were extracted from the results sections of the selected articles. These themes represent the six main areas of PC discussed by the oncologists surveyed or interviewed in the selected studies. The themes include: 1) the value of palliative care, 2) the timing of palliative care referral, 3) the role of the palliative care provider, 4) coordination of care, 5) philosophies of care and 6) the impact of palliative care referral on the patient. The quantitative and qualitative data were synthesized using a complementary approach so that, when combined, they created a complete narrative for each theme. While the survey studies identified particular attitudes or perceptions that oncologists have toward PC, the studies relying on interviews or focus groups added depth to these perceptions and expanded the topics into broader themes. The six themes are summarized in Table 2.

Knowledge of Palliative Care	Barriers to Early Referral
<b>The value of palliative care</b> The majority of oncologists view palliative care as a valuable adjunct to standard care and particularly helpful for the management of physical symptoms and the transition to end-of-life care.	<b>Coordination of care</b> Oncologists express concern about coordinating care with palliative care specialists. They want a clarification of roles and responsibilities and better interprofessional communication.
<b>The timing of palliative care referral</b> There is a lack of consensus among oncologists about when palliative care should be introduced. Most oncologists think referrals should be need-based.	<b>Philosophies of care</b> Some oncologists perceived palliative care as incompatible with cancer therapy because of its association with end-of-life care and its emphasis on quality of life over quantity of life.
<b>The role of the palliative care provider</b> There is a lack of consensus among oncologists about who should deliver palliative care. Some oncologists provide their own palliative care, while others rely on palliative care physicians as co-managers or consultants.	<b>The impact of palliative care referral on the patient</b> Oncologists are reluctant to initiate discussions about palliative care because they are concerned that patients will lose hope and feel abandoned by the oncologist.

**Table 2. Summary of thematic analysis.**

### *Theme 1: The value of palliative care*

More than half of the selected articles explored oncologists' general views about the value and importance of PC for advanced cancer patients. These studies all reported that the majority of oncologists had positive views of PC services and supported concurrent models of PC delivery. Buckley de Meritens et al. (2017) found that 97% of the 145 gynecologic oncology specialists they surveyed believe that PC teams are a useful adjunct to standard patient care. The survey conducted by Johnson et al. (2008) has similar results, with 71% of respondents agreeing that early referrals to PC are beneficial. Other studies reporting that their participants expressed favorable views of PC include those by Le et al. (2014), who conclude that the early introduction of PC is "acceptable to the majority of treating clinicians", and Charalambous et al. (2014), who claim that the majority of their respondents "expressed positive attitudes" towards early PC. The majority of oncologists interviewed by Gidwani et al. (2017), Bakistas et al. (2013), Schenker et al. (2013) and Rhondali et al. (2012) also described PC as a useful addition to standard cancer care that can be used to expand the reach of their own practice and enhance patients' QOL.

Four of the selected studies asked oncologists for their opinions on concurrent models of PC delivery, where oncology and PC teams deliver care simultaneously. The studies by Cherny and Catane (2003), Barni et al. (2011) and Chasen et al. (2014) all used the same survey tool and found that a large majority (77.5-92%) of oncologists agreed or strongly agree that all advanced cancer patients should receive concurrent PC, even if they are still receiving antitumor therapies. They also opposed sequential models of care, with 70-90% of survey respondents disagreeing or strongly disagreeing with the statement "palliative care begins where oncology ends". Ward et al. (2009) similarly found that almost all of their participants (95%) supported concurrent rather than sequential models of PC delivery.

According to the selected literature, oncologists tend to attribute the value of PC services primarily to the benefits it has for symptom management. Johnson et al. (2008) and Ward et al. (2009) both reported that roughly 82.5% of oncologists they surveyed list symptom control as a major reason for PC referral. Symptom control was also the most frequently cited PC trigger reported by oncologists participating in the study by Johnson et al. (2011). The selected studies reveal that oncologists consider PC to be very helpful for symptom control (Buckley de Meritens et al., 2017; Fadul et al., 2014) and that oncologists are more likely to refer a patient to PC if they have uncontrolled symptoms versus no symptoms (Wentlandt et al., 2012). Compared to the other benefits of PC, symptom control was the most well recognized by oncologists. All 34 gynecologic oncologists who participated in the study by Hay et al. (2017) discussed the value of PC services for controlling symptoms at some point during their telephone interview. A number of oncologists interviewed by Bakitas et al. (2012) notably claim that they refer patients to PC for difficult to control symptoms even if the patient is likely to be cured.

The studies also reveal, however, that referrals to PC for symptom control are usually initiated to help patients in the management of physical symptoms, not spiritual or psychosocial symptoms. Johnson et al. (2008) reported that almost one-third of the oncologists they surveyed think that PC is limited to the control of physical symptoms, with 22% remaining neutral. They also found that only 32% of oncologists agree that PC services are the mechanism to deal with psychosocial issues, with a further 45% remaining neutral. Similarly, 66-69% of the participants surveyed by Schenker et al. (2013) and Leblanc et al. (2015) listed pain symptoms as a common reason for PC referral, whereas only 12% reported referring patients to PC for psychological or social support. Oncologists interviewed by Gidwani et al. (2017) viewed PC as having a limited scope, with some participants indicating that the PC physicians they work with focus exclusively



on sedating patients or providing them with pain medication. Furthermore, oncologists' accounts of patients' psychosocial and spiritual issues were observed to be less conceptualized and less detailed than their accounts of patients' physical symptoms (Johnson et al., 2011). Overall, the selected studies revealed a general recognition among oncologists that PC can help patients with the management of physical symptoms, but that the majority of oncologists seldom recognize the benefits of PC for helping patients' address their psychosocial and spiritual concerns.

In addition to symptom management, the majority of oncologists acknowledge that PC services can help patients transition to EOL care. The presence of a terminal illness was cited as a referral trigger for approximately 77% of oncologists surveyed by Johnson et al. (2008) and Ward et al. (2009). Charalambous et al. (2014) reported that 86% of their participants agreed or strongly agreed that PC can help them with the provision of EOL care. Similarly, Buckley de Meritens et al. (2017) indicated that almost all of their study participants (95%) rated PC as "very helpful" for transitioning patients to EOL care. Oncologists interviewed in the selected studies valued the expertise of the PC physician in helping the oncology team transition from curative care to EOL care (Bakitas et al., 2012; Rhondali et al., 2012). Oncologists appreciate the PC physician's ability to reframe goals of care and communicate effectively with cancer patients and caregivers during the transition away from curative care (Rhondali et al., 2012). PC services are thought to be particularly helpful for patients and caregivers who having trouble accepting a prognosis (Rhondali et al., 2012; Bakitas et al., 2012). Four of the selected studies noted that oncologists who frequently provide early referrals to PC usually do so in order to facilitate an eventual transition to EOL care (Le et al., 2014; Bakitas et al., 2013; Schenker et al., 2013; Rhondali et al., 2012). An early referral gives the patient enough time to establish a rapport with the PC physician before the sensitive topic of EOL care needs to be brought up.

## *Theme 2: The timing of palliative care referral*

Despite the fact that a large majority of oncologists recognize that patients can benefit from PC, less than 50% believe that it should be introduced at the time of diagnosis of advanced cancer. When asked about their current referral practices, only 10-45% of oncologists claimed that they regularly refer patients to PC at the time of diagnosis (Hui et al., 2015; Chrambalous et al., 2014; Wentlandt et al., 2012; Fadul et al., 2009). Ward et al. (2009) even found that only half of their participants thought PC *should* be introduced at the time of diagnosis. Furthermore, only 17% of participants surveyed by Buckley de Meritens et al. (2017) think that a PC consultation occurring at diagnosis is appropriate. When Kierner et al. (2010) presented participants with a hypothetical case of a patient with breast cancer, they found that less than 10% of oncologists chose to involve PC at the time of diagnosis of advanced disease.

There is little consensus among oncologists about the appropriate timing for PC referral. Most oncologists believe, however, that PC referrals should be need-based and depend on the patient's functional state and prognosis (Johnson et al., 2011; Schenker et al., 2013; Horlait et al., 2016). This seemingly explains why the top two triggers for PC referral are symptom control and EOL care, as mentioned previously. More than 75% of oncologists say they refer patients to PC when they have uncontrolled symptoms (Charalambous et al. 2014; Buckley de Meritens, 2017) but that they are less likely to refer a patient for uncontrolled symptoms if they have a prognosis of greater than 1 year (Wentlandt et al., 2012). The majority of oncologists (73-97%) also report referring patients to PC when curative therapies have stopped or when they are nearing the EOL (Charalambous et al., 2014; Fadul et al., 2009; Hui et al., 2015; Wentlandt et al., 2012). Buckley de Meritens' (2009) study was an exception, however, with only 42% of respondents agreeing that is appropriate to consult PC when the patient has a life expectancy of <6 months. According

to Johnson et al. (2011), an emphasis on needs-based referrals means that patients who appeared well and did not complain were reportedly perceived to not require PC. Oncologists noted that initiating PC was difficult if the patient was still in good physical condition or responding well to the anti-cancer therapy, even if they were approaching the EOL (Horlait et al., 2016). According to the selected literature, it is particularly challenging for hematologic oncologists to determine the appropriate timing for PC referral because the type of cancers they treat are well maintained and their patients' functional decline can be sudden and unpredictable (Schenker et al., 2013; Horlait et al.; 2016; Bakitas et al., 2012).

### *Theme 3: The role of the palliative care provider*

When it comes to the provision of early PC for advanced cancer patients, the oncologist and the PC provider each play a role. The oncologists surveyed and interviewed in the selected literature had different perspectives on what those roles should be. The oncologists participating in Bakitas et al.'s (2012) study tended to view PC specialists either as co-managers of patient care or as consultants, from whom they request advice only if the situation requires it. Bakitas et al. (2012) explain that involving PC physicians in either of these capacities allows the oncologist to "share the load" of patients with complex care needs, which is particularly beneficial when the oncologist lacks the time or expertise required to meet all the patient's needs. Similarly, Gidwani et al. (2017) found that oncologists usually viewed PC physicians as co-managers or consultants but also found that some oncologists chose to take on the role of PC provider themselves. If an oncologist typically provides PC to their own patients, then it leaves the PC physician without a defined role and the cancer patient without a referral to PC services.

The subset of oncologists who use PC specialists as co-managers of patient care tend to view their main goal as treating cancer, not providing PC. Gidwani et al. (2017) indicated that

these oncologists “did not see themselves as providers of PC due to limited training or time to focus on palliation and a preference for focusing on oncologic skills such as chemotherapy”. The oncologists in this category see a clear role for PC physicians and, as a result, tend to refer their patients to PC earlier and more often. Buckley de Meritens et al. (2017) note that pain control is the domain of PC that oncologists are most willing to co-manage alongside PC physicians, with 69% of their participants agreeing that both teams should be responsible for managing pain. The oncologists interviewed in the selected studies discussed the benefits of co-managing care with PC physicians, indicating that co-management allowed them to focus more on their therapeutic responsibilities (Schenker et al., 2013) and make the best use of their time while working in busy clinics (Leblanc et al., 2015; Rhondali et al., 2012). They explained that involving PC physicians as co-managers early on in the disease trajectory gave the patients time to build rapport with the PC physician to facilitate an eventual transition from curative care to EOL care (Bakitas et al., 2013; Rhondali et al., 2012; Schenker et al., 2013; Le et al., 2014).

Alternatively, oncologists who view PC physicians solely as consultants tend to provide a lot of PC themselves. According to Gidwani et al. (2017), this group of oncologists manage basic physical and psychosocial symptoms and provides patients with needs-based referrals to PC if they have severe symptoms or difficulty accepting a prognosis. Johnson et al. (2011) found that the majority of oncologists they interviewed fell into this category. Most participants explained they were well qualified and able to provide primary PC to their patients with advanced cancer and that they only referred patients to a PC physician if their symptoms became unmanageable. Unlike the oncologists who support co-management, the oncologists who use PC physicians as consultants do not view the PC physician as a partner. Rather, they view their roles as separate and distinct, and often describe PC physicians as a “team of outsiders” (Gidwani et al., 2017) or

a “third-party” (Hay et al., 2017). According to the oncologists interviewed by Hay et al. (2017) and Gidwani et al. (2017), this separation of roles can have a positive effect by allowing patients to talk more openly about the goals of their therapy without feeling pressured by the oncologist. Oncologists do acknowledge, however, that relying on PC physicians solely as consultants can prevent cancer patients from building rapport with the PC physicians (Gidwani et al., 2017). As a result, the PC physician is perceived as a “stranger” who has limited knowledge about the patient and their medical history. This makes it challenging for the oncologists to transition care over to the PC physician at the EOL should cure no longer be an option.

Lastly, there is a minority of oncologists who choose to take on the role of PC provider themselves and, consequently, seldom refer patients to PC specialists. According to the selected studies, there are a variety of reasons why oncologists decide to provide their own PC. First, an oncologist might take on the role of PC provider out of necessity; this is the case for a minority of the oncologists interviewed by Gidwani et al. (2017) who live rural areas with little access to PC services. Second, a number of oncologists view the provision of PC as an integral part of their professional role. The oncologists interviewed by Schenker et al. (2013) note that, before PC emerged as a medical specialty, the oncologist was the one responsible for providing PC to patients. Referring a patient to PC, they argue, would be a neglect of their professional duties. Similarly, the gynecologic oncologists participating in the study by Hay et al. (2017) claimed that they were responsible for taking care of patients “from diagnosis until death” and that the provision of PC was a valued part of their job. Third, some oncologists do not refer patients to PC because they believe that they possess the necessary skills to provide their own PC. Buckley de Meritens et al. (2017) found that oncologists claiming to be more competent in PC tended to refer patients to PC less frequently. In addition, Charalambous et al. (2014) reported that 18% of

their participants had concerns about the expertise of the PC physicians and thought that they could provide better PC themselves. Similarly, oncologists interviewed by Le et al. (2014) did not think that PC providers had additional skills not already available to the treating clinicians. Even though approximately half (45-52.8%) of oncologists claim to have received good training in PC (Chasen et al., 2014; Barni et al., 2011; Johnson et al., 2008; Cherny & Catane, 2003), objective conclusions about their PC expertise cannot be determined from the selected studies.

#### *Theme 4: Coordination of care*

Regardless of whether oncologists provide their own PC or rely on PC physicians as co-managers or consultants, there is widespread agreement that the interprofessional collaboration and coordination of care between the two groups of physicians needs to be improved. According to Buckely de Meritens et al. (2017), 21% of oncologists claim to have had a negative experience working with a PC team that makes them reluctant to consult the team in the future. Oncologists in the selected studies discussed how the overlapping roles and responsibilities of the oncology and PC teams creates confusion and uncertainty about who is supposed to be providing specific services like prescribing pain medication or discussing prognosis (Gidwani et al., 2017; Le et al., 2014). This uncertainty makes oncologists reluctant to refer patients to PC because they fear that the PC physician might contradict the oncologists' opinions on prognosis and treatment and send mixed messages to cancer patients about the treatability of their condition (Leblanc et al., 2015; Le et al., 2014; Schenker et al., 2013). These mixed messages, they argue, have damaged their relationships with patients in the past (Gidwani et al., 2017).

According to the selected literature, many of the oncologists' concerns with coordination of care stem from their desire to maintain control. Oncologists worry that the PC physician will take over patient care and that the oncology team will lose control of what was going on (Hay et

al., 2017; Leblanc et al., 2015) and be left out of treatment decisions (Gidwani et al., 2017). A few of the oncologists in Gidwani et al.'s (2017) study referred to incidents where a member of the PC team switched a patient's treatment regimen without consulting the oncology team. Other oncologists discussed their lack of confidence in PC physicians' knowledge and skill, referring to incidents where PC physicians have missed reversible conditions like pneumonia (Gidwani et al., 2017; Le et al., 2014). They also explained that, because PC physicians tend to lack knowledge about oncology, they often misunderstand the treatability of their patient's condition and fail to appreciate the benefits of cancer treatments (Leblanc et al., 2015; Le et al., 2014).

To improve collaboration, oncologists interviewed in the selected literature supported a clear division of roles and responsibilities and better interprofessional communication (Le et al., 2014; Gidwani et al., 2017; Schenker et al., 2013). They argued that better communication can be achieved by embedding PC services within existing oncology clinics to bring the PC physicians in close proximity to the oncology team (Gidwani et al., 2017; Hay et al., 2017; Le et al., 2014; Schenker et al., 2013). Another popular recommendation was to improve the coordination of care through the use of shared support staff (Gidwani et al., 2017; Hay et al., 2017; Bakitas et al., 2012). This approach relies on nurses, social workers and other allied health professionals to function as a liaison between the oncology and PC teams.

#### *Theme 5: Philosophies of care*

According to the selected studies, some oncologists view PC and oncology as conflicting approaches to care that cannot and should not be delivered at the same time. This view is popular among oncologists who still believe that PC is equivalent to hospice or EOL care. When Hui et al. (2015) and Fadul et al. (2009) asked oncologists if the term "palliative care" was synonymous with hospice and EOL care, 45-60% of them agreed. In the study by Paretti-Watel et al. (2004),

36% of oncologists agreed that PC should be used as a last resort and introduced only after all cancer therapies have failed. Furthermore, a number of oncologists interviewed by Leblanc et al. (2015), Horlait et al. (2016) and Schenker et al. (2013) described PC as EOL or terminal care in their interviews. Leblanc et al. (2015) indicated that hematologic oncologists equated PC with EOL care more frequently than solid tumor oncologists. Other oncologists do not characterize PC as EOL specifically, but rather described PC as a philosophy of care “incompatible with” (Leblanc et al., 2015) or “antithetical to” (Schenker et al., 2013) disease-modifying therapy. They perceive PC as an alternative to cancer therapy and believe that it is inappropriate to refer patients to PC before exhausting all therapeutic options. In other words, these oncologists view the provision of standard cancer care and PC as an either/or proposition.

Though it remains unclear why oncologists think that the philosophies of oncology and PC are incompatible, the results of the selected studies suggest that it has something to do with the curative model of oncology. Oncologists participating in the study by Horlait et al. (2016), for example, discussed how the predominance of the curative model meant that little attention was paid to PC in their practice. They talked about how the medical training they received was geared towards controlling and curing cancer and rarely focused on the provision of PC. One-third of oncologists interviewed by Schenker et al. (2013) shared these views, noting that there was a tendency in oncology to treat either the disease or the symptoms—not both. This curative mindset was most often observed in oncologists working at large academic institutions because of the greater focus on research, innovation and aggressive therapies (Gidwani et al., 2017; Horlait et al., 2016) Oncologists who have been in practice longer or who treat primarily children and young people are also thought to be more cure-focused in their approach to care (Schenker et al., 2013; Johnson et al., 2011).



### *Theme 6: The impact of palliative care referral on the patient*

In many of the selected articles, oncologists expressed concerns about how an early PC referral would be viewed by patients. The oncologists were often reluctant to refer patients to PC early in the disease trajectory because they did not want to appear as though they were giving up or abandoning their patient. Three-quarters of the oncologists surveyed by Buckley de Meritens et al. (2017) were concerned that a PC referral would make patients and family members think they were giving up on them. The oncologists interviewed by Bakitas et al. (2012), Gidwani et al. (2017) and Johnson et al. (2011) also worried that patients would feel abandoned following an early referral to PC. Oncologists also thought that a PC referral would destroy patient hope and cause emotional damage to the patient and their family. Fadul et al. (2009) and Hui et al. (2015) found that 48-60% of survey respondents agreed that the term “palliative care” decreased patient hopes. Similarly, Kiernan et al. (2010) reported that “fear of destroying the patient’s hopes” was the most common reason participants gave for not referring patients to PC earlier. More than half of the oncologists surveyed by Johnson et al. (2008), however, disagreed that patients and family members give up hope when PC is discussed. Based on the selected literature, destroying hope is not a reason why oncologists do not refer patients to PC, but rather a reason why they choose to delay referrals. In the study by Johnson et al. (2008), less than 5% of oncologists selected hope as a reason for *not* referring patients at all.

In many of the selected studies, oncologists also discussed patient reluctance as a barrier to early referral. Ward et al. (2009) reported that 70% of oncologists they surveyed listed patient reluctance as a barrier to early PC referral. Moreover, Charambalous et al. (2014) noted that 26% of oncologists agreed that patients “do not like being referred” to PC services. There was also a perception amongst oncologists that all cancer patients want to do is fight and that they view

discussions about PC as less important than discussions about curative treatments (Le et al., 2014; Schenker et al., 2013; Bakitas et al., 2012). One oncologist interviewed by Schenker et al. (2013) stated: “I know that the patients want to be treated actively and get better, that’s why they come to me or any doctor taking care, not to have palliative care”. Some oncologists delayed PC referrals if they thought that a patient was not psychologically ready to discuss PC (Bakitas et al., 2012) while others attempted to initiate early PC discussions but stopped if the patient expressed extreme sadness or anger (Horlait et al., 2016).

The selected literature revealed that oncologists attribute patient reluctance to the stigma surrounding PC. Oncologists indicated that there was a misunderstanding in the lay community about the concept of “palliative care” and that most people perceived it negatively because they associate it with terminal patient care and imminent death (Le et al., 2014; Bakitas et al., 2012). Oncologists frequently reported avoiding discussions about PC because of this perceived public association between PC and death (Horlait et al., 2016). The stigma surrounding PC meant that oncologists were particularly unlikely to refer patients of certain cultures or faiths (Horlait et al., 2016; Johnson et al., 2011). They cited cultural beliefs about death and dying as a barrier to PC referral and expressed concern that discussions about PC would be viewed as inappropriate or disrespectful by patients who strongly valued hope (Horlait et al., 2016). Some oncologists even mentioned situations where they had to conceal the fact that a patient had a terminal illness in order to respect their cultural beliefs about healing (Johnson et al., 2011).

Importantly, the selected literature shows that oncologists do not personally believe that a PC referral signifies death or abandonment. Both Charalambous et al. (2014) and Wentlandt et al. (2012) found, for example, that under 10% of oncologists they surveyed believed that a PC referral meant that they were giving up. Instead, most oncologists are concerned that patients will

*think* they are being abandoned by the oncologist (Schenker et al., 2013). Such a belief could be a detriment to the confidence and trust that the oncologist has built with the patient. Oncologists also recognize that many of their perceptions about patients' views of PC may not be completely accurate. One oncologist interviewed by Le et al. (2014) highlights this point, stating: "I don't know if a lot of the barriers are our perceived barriers rather than actually what happens when you speak to a patient about it". In addition, oncologists interviewed by Johnson et al. (2011) recognize that patient understanding and acceptance of PC depends largely, "...on what patients are told and how they're told it". Oncologists, therefore, recognize that they have the ability to minimize the emotional impact of PC if they introduce it appropriately.

Oncologists are uncertain, however, about whether or not a strong relationship with a patient can help or hinder discussions about PC. In the studies by Le et al. (2014) and Horlait et al. (2016), oncologists indicated that they thought it was better to wait and establish rapport with a patient before initiating a discussion about PC. Similarly, Hay et al. (2017) found that 27 of 34 participants believe that a strong and long-lasting doctor-patient relationship can make patients more likely to accept a PC referral. A strong rapport, they argued, increases the likelihood that the patient will trust the oncologist's recommendation and makes it easier for the oncologist to explain what PC entails and reduce the stigma associated with referral (Hay et al., 2017). This bond is also thought to motivate the oncologist to obtain the best possible care for their patient, which would typically include a referral to PC (Hay et al., 2017). The results of Johnson et al.'s (2008) survey reflect these views, with 71% of oncologists indicating that it was not difficult to provide referrals to patients that they had a strong relationship with. The selected literature also demonstrates, however, that some oncologists perceive a strong doctor-patient bond as a barrier to early referral because it causes the oncologist to personally identify with the patient, making it

difficult for them to bring up the topic of PC early in the illness trajectory (Horlait et al., 2016; Johnson et al., 2011). In addition, oncologists interviewed by Hay et al. (2017) mention that a strong relationship between an oncologist and their patient can decrease the frequency of PC referrals if the oncologist hopes to maintain that longitudinal relationship by providing PC themselves.

Interestingly then, early PC referrals are described in the selected literature as a double-edged sword. On the one hand, the stigma surrounding PC makes it challenging for oncologists to initiate discussions about PC and provide patients with early referrals. On the other hand, the longer an oncologist waits to introduce PC, the more they reinforce the association of PC with EOL care and death (Gidwani et al., 2017). According to oncologists, providing cancer patients with early referrals to PC is one of the best way to overcome the association between PC and death (Rhondali et al., 2012; Le et al., 2014; Johnson et al., 2011; Schenker et al., 2013; Bakitas et al., 2012). Introducing PC early makes it “less scary” (Bakitas et al., 2012) and “normalizes” PC referral (Le et al., 2014). In order to combat PC stigma, oncologists must confront the loss of hope and emotional damage that it may inflict on patients in the short term to be able to improve PC discussions in the long term.

**Table 3. Articles included in the mixed studies review.**

References	Location	Sample	Purpose	Methodology	Methods	Analysis	Score
Bakitas et al. (2013)	United States	21 oncology physicians, 14 oncology nurse practitioners	To better understand oncologists' perspectives about concurrent oncology palliative care	Qualitative descriptive study	Semi-structured interviews	Thematic Analysis	QUAL 4/6 no reflexivity or sampling
Barni et al. (2011)	Italy	400 medical oncologists	To describe the attitude of Italian oncologists towards palliative care	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 3/3
Buckley de Meritens et al. (2017)	United States	145 members of the Society of Gynecologic Oncology	To describe practice patterns, attitudes and barriers to the integration of palliative care by gynecologic oncologists	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 3/3
Charalambous et al. (2014)	Europe	24 medical oncologists, 14 radiation/clinical oncologists, 11 pulmonologists, 1 thoracic surgeon	To examine the availability of palliative care services and referral patterns of European lung cancer specialists to palliative care	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 3/3
Chasen et al. (2015)	Canada	17 medical oncologists, 16 radiation oncologists, 7 general practitioners in oncology	To assess oncologists' attitudes towards palliative care and the Edmonton Symptom Assessment System (ESAS) at an Ontario Cancer Center in Canada	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 2/3 no sampling
Cherny & Catane (2003)	Europe	895 members of the European Society of Medical Oncology	To obtain valid and accurate descriptive data regarding the practice and attitudes of oncologists in relation to the supportive and palliative management of patients with advanced and incurable cancer and oncologist-related barriers to the provision of optimal supportive and palliative care	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 3/3
Fadul et al. (2009)	United States	100 medical oncologists, 100 mid-level providers	To determine the perception of the impact of the name palliative care compared with supportive care on patient referral	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 3/3

Gidwani et al. (2017)	United States	31 oncologists	To characterize US oncologists' perceptions of primary and specialist palliative care, experiences interacting with palliative care specialists and the optimal interface of palliative care and oncology in providing palliative care	Unspecified, most likely qualitative descriptive	Semi-structured interviews	Matrix and Thematic Analysis	QUAL 6/6
Hay et al. (2017)	United States	34 gynecologic oncologists	To understand how gynecologic oncologists' views influence outpatient specialty palliative care referral	Qualitative Descriptive	Semi-structured interviews	Qualitative analysis using coding and constant comparative approach	QUAL 5/6 no reflexivity
Horlait et al. (2016)	Belgium	15 medical oncologists	To identify the barriers to introducing palliative care into discussions with patients with advanced cancer	Grounded Theory	Semi-structured interviews	Grounded theory principles of open and axial coding	QUAL 5/6 no reflexivity
Hui et al. (2015)	United States	87 oncologists, 95 mid-level providers	To examine the attitudes and beliefs toward palliative care referral among hematologic and solid tumor oncology specialists	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS
Johnson et al. (2011)	Australia	9 general practitioners, 19 oncologists, 5 hematologists, 3 respiratory physicians, 4 colorectal surgeons	To describe doctors' perceptions of barriers to referring patients for specialist palliative care, and to identify triggers and facilitators for referral	Exploratory study	Semi-structured interviews	Thematic Analysis	QUAL 5/6 no reflexivity
Johnson et al. (2008)	Australia	347 oncologists, 95 colorectal surgeons, 166 respiratory physicians, 90 clinical hematologists	To investigate cancer specialists' referral practices, perceptions of, barriers to and triggers for referral of people with advanced cancer to specialized palliative care services	Cross-sectional	Survey	Descriptive Statistics	QUAN OBS 3/3
Kierner et al. (2010)	Austria	176 oncologists	To examine oncologists' attitudes towards palliative care and hospice services in primary metastatic cancer	Cross-sectional	Case-based questionnaire	Descriptive Statistics	QUAN OBS 2/3 no validity

Le et al. (2014)	Australia	28 lung cancer clinicians from a variety of disciplines	To explore lung cancer specialists' perceptions about the potential value and barriers to implementation of early referral to palliative care for all patients with metastatic lung cancer	Exploratory study	Focus groups and interviews	Thematic Analysis	QUAL 5/6 no reflexivity
LeBlanc et al. (2015)	United States	23 hematologic oncologists, 43 solid tumor oncologists	To explore differences in referral practices and views of palliative care among hematologic oncologists and solid tumor oncologists practicing at academic centers with well-established palliative care programs	Mixed methods	Survey and semi-structured interviews	Descriptive Statistics & qualitative analysis with a constant comparative approach	QUAL 5/6 no reflexivity
Peretti-Watel et al. (2004)	France	217 oncologists, 83 HIV specialists	To investigate and compare opinions towards palliative care among HIV specialists and oncologists	Cross-sectional	Survey	Cluster Analysis	QUAN OBS 3/3
Rhondali et al. (2013)	United States	17 medical oncologists	To examine oncologists' perceptions of the supportive care program at M.D. Anderson Cancer Center and to determine whether renaming "palliative care" to "supportive care" influenced communication regarding referral	Grounded theory	Semi-directed interviews	Thematic Analysis	QUAL 5/6 no reflexivity
Schenker et al. (2013)	United States	74 oncologists	To explore oncologist factors that influence referrals to outpatient palliative care	Qualitative interview study	Semi-structured interviews	Thematic Analysis	QUAL 5/6 no reflexivity
Ward et al. (2009)	Australia	78 medical oncologists, 37 medical oncology trainees	To investigate the attitudes of medical oncologists and trainees in medical oncology toward palliative care and collaboration with specialist palliative care	Cross-sectional	Survey	Descriptive Statistics and Thematic Content Analysis	QUAN OBS 3/3
Wentlandt et al. (2012)	Canada	226 medical oncologists, 302 radiation oncologists, 75 surgical oncologists	To describe current referral practices of oncologists to specialized palliative care and define demographic characteristics, practice situations, and opinions associated with referral	Cross-sectional	Survey	Descriptive statistics	QUAN OBS 3/3

### **3.4 Discussion**

The MSR and narrative synthesis presented in this thesis combines the results of 21 studies investigating the attitudes and perceptions of oncologists toward PC for advanced cancer patients. More than half of the articles selected for inclusions in the MSR were published within the last 5 years, likely due to the recent surge in evidence supporting the effectiveness of early PC interventions for advanced cancer patients. The results of this MSR reveal that the majority of oncologists recognize that PC is a valuable addition to standard cancer care and that it can help patients manage physical symptoms and transition to EOL or hospice care. The results also indicate, however, that oncologists seldom refer patients to PC services to address psychosocial concerns. Though it remains unclear why oncologists refer less frequently for reasons related to psychosocial domains of care, some oncologists surveyed or interviewed in the selected studies indicated a lack of awareness about PC specialists' ability to address psychosocial symptoms. In other studies, researchers have found that oncologists' ability to detect the psychosocial needs of patients pales in comparison to their ability to detect physical symptoms (Okuyama et al., 2011; Rodriguez et al., 2010; Newell et al., 1998). It has also been shown that patients and caregivers are less likely to disclose psychosocial concerns (Heaven & Maguire, 1997).

The results of the MSR also highlight the heterogeneity of oncologists' perceptions about the appropriate timing for PC referral and the roles and responsibilities of the PC provider. While some oncologists view the PC physician as a co-manager of care and choose to refer early, others provide much of their own PC and choose to refer patients later in the disease trajectory or not at all. According to the results of the MSR, there are numerous reasons why an oncologist might be reluctant to refer a patient to PC. Some oncologists view the provision of PC as part of their role while others have concerns about communicating and coordinating care with the PC team. There



is also a predominant view among oncologists that PC is incompatible with ongoing cancer care and should only be introduced after curative therapy has been stopped. Furthermore, oncologists are hesitant to initiate discussions about PC because they do not want to destroy patient hope or make them feel abandoned. These perceived patient-level barriers to early PC are similar to the patient-level barriers oncologists experience when initiating EOL care discussions (Granek et al., 2013), recruiting patients for PC research (Kars et al., 2016), or delivering bad news (Bousquet et al., 2015). Although negative views of PC are found to be prevalent among patients and their caregivers (Westerlund et al., 2018; Zimmerman et al., 2016; McIlfatrick et al., 2013; Hirai et al., 2011), many of these negative views are thought to originate from interactions with healthcare professionals themselves who present PC as a last resort, often apologetically (Zimmerman et al., 2016).

Taken together, what the results of this MSR indicate is that oncologists' perceptions and attitudes toward PC are based on a combination of knowledge factors and identity factors. Many oncologists who perceive PC as being equivalent to EOL care, for example, might simply be ill informed about the contemporary definition of PC and the recent recommendations of the ASCO and the NCCN. In other words, oncologists' misconceptions about PC can be attributed, at least in part, to challenges in knowledge translation. Researchers estimates that it takes an average of 17 years for research evidence to be adopted in clinical practice (Morris et al., 2011). It makes sense then, that a number of oncologists are still unaware or unconvinced by the recent evidence supporting early PC. The results of the MSR further indicate, however, that oncologists' views of PC depend not only on their PC knowledge but also on how they see and understand themselves. Oncologists understanding of their field of practice, their professional role and their relationships with patients all appear to have an impact on how they perceive PC.

The referral practices of oncologists, then, are perhaps best understood if framed within the context of professional culture and identity. Pippa Hall (2005) describes the professional culture of a health care worker as the combination of “values, beliefs, attitudes, customs and behaviors” of a particular health care profession. Professional identity is the self-concept that results from the internalization of a professional culture (Cruess et al., 2014). The professional cultures and identities of various types of health care workers have already been described in the literature, including the identities of hospital pharmacists (Rosenthal et al., 2015), social workers (Beddoe, 2013), nurses (Ohlen & Segesten, 1998) and physicians (Stern et al., 2006; Roberts, 1989). The professional culture of the physician is built on a mandate of providing excellent and innovative biomedical care with the goal of curing disease (Johnson et al., 2008; Roberts, 1989). Physicians often measure success based on their ability to extend or preserve life and are trained to take charge, make decisions and use objective data to solve problems (Roberts, 1989).

Oncologists embody this professional culture well; they are a prototypical example of a type of physician who is trained to treat and cure disease. Their efforts to find a cure for cancer are often depicted as a war and described using metaphorical language like ‘battle’, ‘fight’ and ‘survivor’. As a result, certain oncologists have an aversion towards death and view the loss of a patient as a personal and professional failure (Baider & Wein, 2001). This is quite different from how PC physicians approach patient care. They value medical interventions for their capacity to improve quality of life—not quantity of life—and provide therapies with the goal of alleviating suffering instead of curing disease (Kozminsky et al., 2011). The PC physician treats the person behind the disease instead of treating the disease itself. They are not death-denying nor do they view death as a loss or failure. In these ways, the PC physician does not fit the traditional mold of what it means to be a physician and does not necessarily embody all of the values commonly

associated with the professional culture of oncology. It seems likely then, that the oncologist and the PC physician have internalized two distinct but related professional cultures.

The differences between the professional cultures of oncology and PC could explain why oncologists are reluctant to provide patients with early referrals to PC. According to Pippa Hall (2005), differences in professional cultures can act as a barrier to interprofessional collaboration by negatively affecting the communication, trust and respect between professional groups. These differences can also prevent oncologists and PC providers from developing shared goals and limit the understanding of and respect for each other's roles and responsibilities (Hall, 2005). For example, an oncologist who views discussions about goals of care as falling within their own professional domain will likely perceive that the PC physician is overstepping boundaries when they discuss treatment options or DNR status with a patient. The results of the MSR appear to reflect this type of "clash" between the professional cultures of oncology and PC. Oncologists in the selected studies describe the philosophies of oncology and PC as incompatible and suggest that there is a lack of mutual trust and respect between the two physician groups. They talk about their concerns with regards to the overlapping roles and responsibilities of the oncology and PC teams and underline the problems that they encounter when communicating with PC physicians.

Until recently, no studies have investigated how conflicting professional cultures can act as a barrier to interprofessional collaboration between oncologists and PC physicians. Attitudinal barriers have been identified between oncologists and primary care physicians in studies of cancer survivorship (Barnes et al., 2017; Cheung et al., 2013; Potosky et al., 2011) and between ICU clinicians and PC specialists (Billings et al., 2006), but never between oncologists and PC physicians. Recently, however, Gagnon et al. (2018) held deliberative stakeholder consultations with oncologists and PC providers during which time they asked the stakeholders to discuss the

implementation of a new genomic test for pediatric oncology patients with treatment-resistant glioblastoma. They observed a strong underlying conflict between the professional cultures of the oncologists and the PC providers and found that this conflict acted a barrier to de-escalating curative care. Gagnon et al. (2018) argued that treating the “curative culture” of oncology could help to improve the interprofessional collaboration and coordination of care between the two physician groups.

The results of the MSR indicate, however, that distinct professional cultures not only exist between oncology and PC, but also within oncology. The diversity of oncology specialties and the variety of practice environments appear to foster different professional subcultures and identities which result in oncologists having heterogeneous perceptions of PC and differences in their referral practices. The MSR demonstrates, for example, that gynecologic oncologists are more likely to perceive PC as an integral part of their own professional role and that hematologic oncologists tend to interact less frequently with the PC team because of the unpredictable nature of the cancers they treat. The MSR also found that oncologists working in large academic centers tend to place greater value on curative care because of their improved access to clinical trials and innovative therapies. What this MSR suggests then, is that oncologists’ referral practices and views of PC are not only based on their PC knowledge, but also on their professional values and preferences in addition to their personal experiences with and exposure to PC services. In other words, oncologists’ perceptions of PC and corresponding referral practices might depend largely on who the oncologist *is* rather than simply what they know or do not know about PC.

Even patient reluctance, which is frequently mentioned by oncologists as a barrier to PC referral, might actually be a reflection of the oncologist’s own professional culture and identity. In the selected studies, oncologists talk about how important it is that cancer patients do not feel

abandoned. Oncologists present this argument in a way that makes it seem as though they are protecting the patient from emotional distress when, in reality, it might actually be a reflection of their own discomfort with abandoning the fight for a cure. Curing disease is a professional value that sits at the core of an oncologist's professional identity and it can affect their judgement even without awareness. The values oncologists have internalized could be subconsciously driving their views of PC and decisions about whether or not to refer a patient to PC (Hall et al., 2005). For example, oncologists could be projecting their curative ideal onto patients when they assume that patients only want to fight and do not want to discuss PC. In actuality, Schenker et al. (2014) found that patients with unmet PC needs do see a higher need for PC referral and would be eager and willing to consult with a PC specialist if recommended by their oncologist. The perceived patient-level barriers to early PC referral, therefore, might not be the result of patient opinion but rather of oncologists projecting their values onto patients. More research needs to be conducted, however, to confirm this theory. Although some oncologists interviewed in the selected studies acknowledged that their curative mindset could be affecting their views of patients, the majority did not express any awareness of how their perceptions of patients could be affected by the beliefs, values and biases of their medical specialty.

### **3.5 Implications**

#### *Interprofessional socialization*

If the professional culture and identity of the referring oncologist is contributing to the late PC referral practices in oncology, then interventions targeting the formation of professional identity might address this issue. Professional identity formation is a process whereby medical students internalize a particular professional culture through education and training (Cruess et al., 2014). Later, the facts and skills the students have learned shape and inform their approach to

care and medical intervention (Cruess et al., 2014). It is during medical school that students are socialized into the types of role relationships expected within their particular work environment (Pratt et al., 2014). It seems logical then, that if we want to “treat” problems associated with the curative culture of oncology, then we should intervene before a student’s professional identity is fully formed. A strong professional identity among a group of medical specialists, however, has been shown to positively impact the quality of care and the overall work productivity within a specialty (Molleman & Rink, 2015). Changing the professional identity of the oncologist could diminish these positive outcomes. The solution then, is not to weaken the professional culture of oncology that currently exists, but to build on it.

According to the literature, fostering collaboration between various physician groups can be achieved by broadening existing professional identities into dual identities composed of both a professional and an interprofessional identity (Khalili et al., 2013; Baker et al., 2011; Carpenter & Dickinson, 2008). Khalili et al. (2013) note that an interprofessional identity can help health professionals look beyond their own professional roles and responsibilities to better understand how the roles of all health professionals combine to result in effective collaboration. According to Khalili et al. (2013), the first stage of dual identity development requires the creation of an open and trusting environment where students can address their prejudices and misconceptions about other medical professionals. It is only once those initial barriers are broken down that the two groups of professionals can begin to understand and appreciate each other’s roles, skills and knowledge, and later talk about how to work collaboratively across professions (Khalili et al. 2013). The goal of dual identity formation is to encourage students to view themselves as both a member of their own medical specialty and as a member of an interprofessional community (Khalili et al., 2013; Baker et al., 2011; Bridges et al., 2011; Hall, 2005).

Alternatively, oncology fellows might choose to adopt a dual identity by becoming certified in both oncology and PC. As Hui et al. (2015) explain, the rapidly growing field of palliative oncology consists of physicians trained initially as oncologists who develop a strong interest in managing the physical and psychosocial impacts of cancer. While some palliative oncologists are able to provide specialist PC themselves as a member of interdisciplinary PC team, others are well trained to recognize when a patient's supportive care needs merit a referral to specialist PC. According to Hui et al. (2015), palliative oncologists are unique because, in addition to being able to provide supportive care to patients, they have a refined understanding of complex cancer biology and an appreciation for the risks and benefits of innovative anticancer therapies. This knowledge allows palliative oncologists to make treatment recommendations that are tailored to a particular patients' prognosis, comorbidities, values and lifestyle. Furthermore, because of their experience working as part of interdisciplinary PC teams, palliative oncologists are exposed to a variety of professional subcultures allowing them to understand and appreciate the values, preferences and roles of experts working in both oncology and PC.

Two of the best ways to help students expand their professional identities are through the use of role models and embedded clinics. Role modeling is an educational strategy that has risen in popularity over the years primarily because of its association with the process of professional identity formation (Jarvis-Selinger et al., 2012; Haidet & Stein, 2006; Paice et al., 2002; Kenny et al., 2003; Maudsley et al., 2001). Pratt et al. (2006) found that role models play a critical role in identity learning by validating students newly constructed identities. Pairing oncology students with mentors in PC could help oncologists gain interprofessional identities by challenging their misconceptions about PC and helping them understand the roles and skills of the PC physician. Hui et al., (2015) also see an important role for palliative oncologists in becoming mentors and

educators for oncology colleagues and trainees. The use of role models can be made a priority by making PC rotations mandatory for medical residents or fellows in oncology (Wong et al., 2016; Khot et al., 2011; von Gunten et al., 2005). Identity formation and interprofessional collaboration can also be facilitated by embedding PC services within existing oncology clinics (Hui & Bruera, 2016). Placing oncologists and PC professionals in proximity of one another can increase the number of opportunities for learning and collaboration (Hui & Bruera, 2016). However, current evidence supporting the use of embedded clinics remains limited (Einstein et al., 2017; Muir et al., 2010). Further research is needed to investigate the value of embedded clinics for improving patient care and increasing collaboration across specialties.

### *Physician education*

In qualified professionals who have already fully internalized their professional cultures, adjusting or expanding their professional identity can be a challenge (Irvine et al., 2002). In these oncologists, the key to improving PC referral practices will be to increase their awareness about what the term “palliative care” means and broaden their views of the benefits of PC services to include the management of patients’ psychosocial symptoms. Many of the oncologists surveyed or interviewed in the selected studies perceive PC as limited to the control of physical symptoms or the provision of EOL care. In actuality, PC experts can also help by treating the psychosocial, spiritual and practical needs of patients, helping to coordinate care across disciplines, facilitating conversations about prognosis and treatment and acting as a support system for family members.

A number of continuing education projects have been designed to address these beliefs and misconceptions about PC in attending oncologists (Yamamoto et al., 2015; Robinson et al., 2004; Vangeest, 2001). The Education in Palliative and End-of-life Care (EPEC) project, for example, aims to increase physician knowledge of PC with a train-the-trainer strategy (Robinson



et al., 2004). Physicians interested in being EPEC Trainers must attend a 2 ½ conference after which point they are able to teach others about PC using the EPEC Curriculum (Robinson et al., 2004). Similarly, in Japan, the Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE) is a 2-day program that is designed to provide formal PC education and training to all physicians caring for cancer patients through the use of workshops, plenary sessions and small group discussions (Yamamoto et al., 2015).

Oncologists can also benefit from educational strategies to learn how to break bad news. As mentioned previously, the majority of patients want their oncologist to communicate openly about their disease (Hagerty et al., 2004) and show interest in discussing specialty PC (Schenker et al., 2014). Oncologists, however, are reluctant to initiate conversations about PC because of its association with terminal illness and death. Owing to this stigma, PC has garnered a reputation of being considered “bad news”. Educational tools designed to help oncologists deliver bad news can therefore be used to initiate conversations about PC. Back et al. (2007), for example, held a 4-day Oncotalk workshop that taught oncology fellows appropriate communication skills to be used at various stages in the illness trajectory. Although the ultimate goal is to reduce PC stigma over time, workshops like Oncotalk can be used in the meantime to help oncologists bring up PC in a way that minimizes discomfort for themselves and for patients.

### *Public Awareness*

Interventions targeting oncologists alone, however, are unlikely to drastically change PC referral practices (Greco & Eisenberg, 1993). It is also important to educate patients and family members about PC so they are more open to discussing PC and so that their oncologist is more confident initiating conversations about PC early in the disease trajectory. Hoerger et al. (2017) found, for example, that patients who were presented with a summary of the Temel et al. (2010)

study expressed greater interest in PC services and viewed PC as more efficacious and less scary compared to controls. Furthermore, Matsuyama et al. (2011) argue that the disproportionately low use of PC services among African Americans could be due to their lack of knowledge about PC and the availability of PC services. Schenker et al. (2014) discovered, however, that even when advanced cancer patients are well educated about PC and perceive a high need for specialist PC services, they do not have an increased likelihood to request it. Schenker et al. (2014) speculate that these results are due to the power imbalances that exist between patients and physicians. Additional work needs to be done, however, to determine the exact barriers to patient-initiated referrals and to understand whether or not patient education can have an impact on the number of early referrals made to PC.

### **3.6 Limitations**

This review has a number of limitations. First, the diversity of participants recruited in the studies makes it difficult to generalize results. It synthesizes the views of different types of oncologists (medical, surgical, radiation) working in a variety of medical fields (pulmonology, gynecology, hematology, etc.) at various institutions located in dozens of countries. Every one of these variables is hypothesized to have an effect on oncologists' views of PC. Those working in research or academic centers, for example, are more focused on delivering aggressive treatments and are reported to collaborate less frequently with PC services (Barni et al., 2011; Gidwani et al., 2017). The two biggest outliers found in the selected studies are the gynecologic oncologists and the hematologic oncologists. Whereas gynecologic oncologists reported less PC referrals due to their unique longitudinal relationship with their patients (Hay et al., 2017), the hematology oncologists reported referring less frequently because of their unique patient population whose diseases can be well maintained and unpredictable (Bakitas et al., 2012; Horlait et al., 2016).

Second, a sample selection bias is probable because the oncologists participating in the selected studies likely had a greater interest in PC and more experience in delivering PC services. In the majority of the selected studies, the researchers used a convenience sample of participants. Invitations were usually sent out to all the members of a particular medical society or to every oncologist working in a specific cancer center. Therefore, the oncologists agreeing to participate in the study likely had existing interests in PC or were eager to learn more about it. The studies also do not account for oncologists who are dually certified in both oncology and PC. Moreover, a few of the selected studies were conducted at cancer centers where concurrent models of oncology and PC have existed for years (eg. Bakitas et al., 2012). At these centers, oncologists are not only more aware of what PC is and how it can help patients, but they also work in close proximity to PC services, giving them frequent opportunities to collaborate with PC experts.

Third, the approaches used in this MSR to synthesize the literature and extract themes are inherently flawed. As mentioned previously, one of the weaknesses of narrative synthesis is that it lacks transparency because it requires interpretation and creativity on the part of the researcher (Dixon-Woods et al., 2005). Narrative synthesis is also a relatively new methodology and lacks the substantial literature backing that other approaches have (Mays et al., 2005). In addition, the flexibility inherent to thematic analysis means that researchers can have broad interpretations of a dataset, leading to problems with consistency and cohesion (Holloway & Todres, 2003). A second independent reviewer is often suggested to mitigate the problems with consistency and cohesion, however, only a single reviewer was used for the purposes of this thesis.

Finally, it is possible that the perceptions of oncologists described in the results section of this manuscript are less relevant today than they would have been 10-15 years ago. Appreciation for the psychosocial aspects of disease is growing and PC is increasingly being recognized as an

integral part of ongoing cancer care (Page & Adler, 2008). It follows then, that the oncologists completing residency today might have different views of PC than those studied in this thesis.

### **3.7 Conclusion**

Despite these limitations, this MSR and narrative synthesis found that oncologists have a variety of opinions about what PC is, when it should be introduced and how it should be used in oncology. This systematic review corroborates existing concerns about the lack of PC knowledge among oncologists and presents a novel finding detailing the impact of oncologists' professional culture and identity on their perceptions and use of PC services. To gain a better understanding of how the professional culture of oncology impedes the utilization of PC, future research should investigate the differences between the professional cultures of oncology and PC with the goal of developing new strategies to overcome these differences. As the number of people diagnosed with cancer continues to increase, so too must our efforts to improve the delivery of PC to ensure that all cancer patients, regardless of the stage of their illness, receive appropriate supportive care to maximize their quality of life.

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## **Bridging Manuscripts**

Based on the results of the MSR described above, oncologists appear to have generally favorable views of PC and believe it can be beneficial for patients with advanced cancer. Many oncologists also believe, however, that PC is limited in scope and should only be introduced near the end of life unless the patients' supportive care needs are complex and the oncologist requires support. This lack of knowledge on the part of referring oncologists, however, is only part of the problem. The systematic review further revealed that delays in PC referrals can be also attributed to conflicts between the professional cultures of oncology and PC. Given that there appears to be significant physician-level barriers to early PC referral, this raises interesting questions about the appropriateness of oncologist-driven models of PC referral that are popular across the globe.

In addition to systematically reviewing the literature on oncologists' perceptions of PC, this thesis engages in an critical analysis of the ethical issues related to oncologist-driven models of PC referral. Are oncologists the ideal gatekeepers of PC? Are oncologists' decisions to refer a patient to PC in line with the best interests of patients diagnosed with advanced cancer? How do the heterogeneous referral practices of oncologists affect patient care? Are the current PC referral practices in line with the professional codes of ethics? Manuscript 2 attempts to answer some of these questions by drawing on established principles of biomedical ethics and the results of the MSR. This manuscript is meant to build on the body of literature investigating the ethics of PC and EOL care by serving as an introduction to the ethics of early PC interventions and models of early PC referral and delivery.

## **Chapter 4 - Manuscript 2:**

### **The ethics of palliative care gatekeeping in oncology**

#### **Abstract**

**Background:** Current models of palliative care referral in oncology rely on the oncologist as a gatekeeper. In their role as palliative care gatekeeper, the oncologist is tasked with identifying patients' unmet supportive care needs and deciding whether or not these needs merit a referral to palliative care. Given that oncologists knowledge and perceptions of palliative are thought to influence their referral decisions, this raises important ethical questions about the appropriateness of oncologist-driven models of palliative referral. **Objectives:** The purpose of this manuscript is to analyze oncologist-driven models of palliative care referral from an ethical lens. **Methods:** A principlist framework was used to guide a critical analysis of the ethical issues associated with palliative care gatekeeping in oncology. Arguments and counter arguments were presented for each principle and supported by the results of the systematic review (Chapter 3) and Canadian codes of ethics. **Results:** By providing advanced cancer patients with early referrals to palliative care, oncologists would be supporting the patients' best interests, reducing the likelihood of harm and promoting their autonomy. Under the current oncologist-driven models of referral, however, access to these advantages is inequitable owing to the variable referral practices of oncologists. **Conclusions:** As the gatekeepers of palliative care services for cancer patients, oncologists have

an ethical responsibility to refer advanced cancer patients to palliative care if they are not able to provide high quality supportive care themselves. Since oncologists often delay referrals under the current referral models, new strategies need to be implemented to enhance the gatekeeping role of the oncologist or to supersede it.

#### **4.1 Introduction**

Currently, oncologist-driven models of PC referral are the norm worldwide (Hui and Bruera, 2016). According to these models, the oncologist acts as a PC gatekeeper by identifying patients with supportive care needs and deciding if and when these patients require a referral to PC. Although medical gatekeeping was initially developed in order to cut healthcare spending through the reduction of unnecessary medical testing (Brekke et al., 2007), the main purpose of gatekeeping today is to ensure that patients receive healthcare services that are appropriate to their needs (Willems, 2001). As the gatekeepers of PC for advanced cancer patients, oncologists are given the power to decide if and when an advanced cancer patients should receive a referral to consult with a PC physician. The gatekeeping power granted to oncologists raises interesting ethical questions about whether or not oncologists have an moral responsibility to provide early PC referrals to advanced cancer patients and whether or not their current gatekeeping practices in oncology are ethically justifiable. Furthermore, given that the primary oncologist's values and perceptions appear to impact their referral practices, it is worthwhile to inquire to what extent oncologists should be permitted to involve their perceptions of PC in decision-making.

Ethical issues in healthcare gatekeeping were first examined by American doctor and bioethicist Dr. Edmund Pellegrino. In the paper "Rationing health care: the ethics of medical gatekeeping", Pellegrino (1986) describes the physician as a *de facto* gatekeeper because of their role in recommending which tests, treatments, medications or consultations to give to patients.



He explains that the physicians' role as a *de facto* gatekeeper imposes a moral obligation on them to use only the most appropriate means to cure a disease or relieve suffering (Pellegrino, 1986). This gatekeeping role, he argues, is unavoidable. The fiduciary relationship that exists between a patient and a gatekeeper requires the patient to place trust in the physician to help them make decisions that maximize their wellbeing. In return, the physician has a responsibility to offer the patient the best available medical care. In situations when resources are limited, the gatekeeper's responsibility to their patient can conflict with their responsibility to restrict the consumption of resources for the collective good (Weinstein, 2001). Ultimately, however, ethicists agree that it is unethical to restrict a patient's access to care purely based on financial or economic reasons (Kassirer, 1998; Toulmin, 1986; Dyer, 1986; Angell, 1985).

In their role as PC gatekeepers, oncologists are tasked with determining whether or not PC services are appropriate for their patients and at which point in the disease trajectory a patient should be referred to PC. This role not only requires oncologists be able to recognize supportive care needs, but it also necessitates that the oncologists make a judgement about whether or not these needs warrant a PC referral (Hui & Bruera, 2018). The systematic mixed studies review (MSR) contained in Chapter 3 of this thesis found that these judgements can be influenced by a variety of factors including the patient's prognosis and symptom burden as well as the referring oncologist's education, experience and personal values and attitudes towards PC. Is it ethically justifiable then, to base PC referrals on the judgements of oncologists? In their capacity as *de facto* gatekeepers of PC, do oncologists have an ethical responsibility to refer all cancer patients with an advanced diagnosis to PC? To answer these questions, oncologist-driven models of early PC referral will be analyzed according to the ethical principles of beneficence, non-maleficence, patient autonomy and justice and supported by the results of the MSR.

## 4.2 Framework

This manuscript provides a brief overview of the ethical issues related to PC gatekeeping using the four principles approach to ethical analysis developed by Beauchamp and Childress (2001). Principlism is a normative ethical framework that was designed for practical decision-making in health care settings (Beauchamp & Childress, 2001). This framework is based on assessing and balancing the four fundamental ethical principles of medical ethics: beneficence, non-maleficence, autonomy and justice (Beauchamp & Childress, 2001). Principlism combines both top-down and bottom-up approaches to ethical analysis and, therefore, borrows elements from various moral theories as well as specific cases or contexts to inform the application of the four principles to a dilemma (Beauchamp & Childress, 2001). Given that the topic of this thesis is about the referral decisions of oncologist gatekeepers, it seemed logical to analyze the ethics of PC gatekeeping by employing the ethical framework used by physicians in everyday practice. In addition, this manuscript will reference the professional codes of ethics used by physicians who work in Canada. By using a principlist paradigm and professional codes of ethics to frame the ethical issues in PC gatekeeping, it will hopefully make it easier to project these issues back to the physician gatekeepers in a way that is familiar and easy to understand.

The ethics of PC gatekeeping will be examined by exploring the various ways in which oncologist-driven models of PC referral can violate the ethical principles of beneficence, non-maleficence, autonomy and justice. Arguments and counter arguments will be presented for each principle and backed by evidence taken from the results of the MSR and other outside literature. For certain principles, the current referral practices of oncologists will also be compared to the Canadian Medical Association's Code of Ethics ([CMA], 2004) and the Code of Ethics of Physicians published by the Collège des médecins de Québec (2018).

## **4.3 Results**

### **4.3.1 Beneficence**

The oncologist is a medical professional and therefore has an ethical and legal duty to be of benefit to patients (Picard & Robertson, 2007). More specifically, oncologists have a fiduciary responsibility to provide care that is in the patients' best interest: "A physician's paramount duty is to protect and promote the health and well-being of the persons he attends to, both individually and collectively" (Collège des médecins de Québec, 2018). They can accomplish this either by providing appropriate medical care themselves or by referring a patient to specialty care in their capacity as a medical gatekeeper. Fulfilling this fiduciary responsibility ensures that oncologists adhere to the ethical principle of beneficence (Beauchamp & Childress, 2001). The difficulty with ensuring beneficence is that the concept of "best interest" is inherently subjective. What is considered to be in the best interest of one cancer patient might not be in the best interest of a similar patient. Some patients, for example, place a high value on physical wellbeing while others consider psychosocial wellbeing or the wellbeing of their family to be the most important. To ascertain what type of care is in the patient's best interest, oncologists should start by asking patients about their goals and needs (von Gunten et al., 2000).

Determining best interest can also be problematic because medical specialists are prone to perceive best interests with the theoretical biases and predispositions of their specialty (Rollin, 2006). Oncologists might therefore be inclined to measure a patient's best interests in terms of their physical needs and overlook their psychosocial and spiritual needs (Sharkey et al., 2010). It is therefore likely that decisions made on behalf of patients by oncologists will not truly reflect the patients' best interests. When defining best interests, the oncologist should try to take patient considerations (ie. values and beliefs) as well as medical considerations (ie. which treatments are

available and how likely they are to provide benefit) into account. Although these considerations can often be in conflict, the decision about whether to promote patient or medical considerations should be based on whichever outcome most benefits the patient and should not depend on the intellectual convictions or emotional impulses of the oncologist (Pellegrino & Thomasma, 1987).

When it comes to the provision of PC, it is difficult to imagine a scenario where a timely referral to PC would *not* be in the best interest of an advanced cancer patient. The literature on the effectiveness of early PC shows that it can offer numerous benefits to cancer patients such as improvements in QOL, psychosocial wellbeing and satisfaction with care (Haun et al., 2017). A delayed referral to PC would therefore violate the principle of beneficence seeing as it denies patients timely access to the benefits of PC interventions. A lack of referral, however, could be ethically justifiable if the oncologist is able to meet all of the patient's supportive care needs by delivering PC themselves. The MSR results indicate that many oncologists do choose to deliver their own PC but the quality of PC they provide has yet to be determined. Importantly, the CMA Code of Ethics (2004) states that physicians should "recognize [their] limitations and, when indicated, recommend or seek additional opinions and services." Therefore, if an oncologist is unable to provide high quality PC to their patients, then they have an ethical responsibility to defer care to the greater expertise of the PC physician. A lack of referral to PC may also be ethically justifiable in situations where the oncologist believes that an early referral would do more harm than good. For example, oncologists interviewed in the selected studies thought that a PC referral could be harmful for patients of certain cultures or faiths. In general, however, most oncologists described PC as a useful addition to standard cancer care that was relatively risk-free. The potential harms they did mention, such as emotional distress or mixed messages, can be mitigated through improvements in communication and coordination of care.

### **4.3.2 Non-maleficence**

In accordance with the ethical principle of non-maleficence and the CMA Code of Ethics (2004), early referrals to PC can also be an effective way to reduce the harms associated with the care of advanced cancer patients. Non-maleficence refers to the physician's moral responsibility to minimize or avoid causing harm to patients (Beauchamp & Childress, 2001). It is well known that many of the therapies used to treat cancer can have severe side effects like pain and nausea (Vainio et al., 1996). Introducing PC can actually minimize these harms and help patients better tolerate their anticancer drugs or treatments. Furthermore, by having discussions about goals of care with patients, PC physicians can make the risks and benefits of anticancer therapies explicit and help patients avoid the harms associated with futile treatments (Rugno et al., 2014; Harris & Murray, 2013).

Initiating early discussions about PC services can also encourage the oncology team to be transparent with patients about their prognosis and treatment plans. Previous research has shown that patients diagnosed with advanced cancer want their oncologist to be realistic and open when talking about prognosis (Hagerty et al., 2004). The results of the MSR found, however, that some oncologists choose to restrict information about prognosis and avoid talking about PC because they mistakenly believe that disclosure will cause more harm than good. In actuality, adopting an avoidant approach and restricting information from patients can actually have adverse effects on the doctor-patient relationship and cause more harm in the long-run (Hancock et al., 2007).

### **4.3.3 Autonomy**

Often conflicting with the principles of beneficence and non-maleficence is the principle of autonomy (Pellegrino & Thomasma, 1987). Autonomy refers to the physician's ethical duty to respect a patient's capacity for self-determination (Beauchamp & Childress, 2001). Autonomy

recognizes the ability of a competent patient to participate in decisions about their medical care including the weighing of risks, benefits, and alternatives of a proposed intervention in order to ensure that they receive care that best reflects their goals, preferences, and values (Schenker et al., 2011). Shared-decision making (SDM), which is increasingly being recognized as the ideal model of decision-making in healthcare, is designed to support patient autonomy while also accounting for physician expertise. SDM is a process which relies on the active exchange of information between a patient and their physician with the goal of reaching a consensus when making a decision about a treatment plan (Charles et al., 1997).

When it comes to SDM in PC, research shows that the majority of patients do not achieve their preferred level of involvement in decision-making because decisions are often delayed and alternatives are seldom discussed (Bélanger et al., 2011). In order to respect patient autonomy, oncologists should be disclosing any relevant information about clinical decisions that affect the patient's health and wellbeing (CMA, 2004). This is backed by the doctrine of informed consent, which states that physicians have a responsibility to disclose information about the risks and benefits of any proposed intervention or therapy, the anticipated outcomes, and the available alternatives (Evans & Henderson, 2006). Discussing treatment options and alternatives with patients ensures that they are able to make informed decisions about whether or not to consent to cancer treatment. It would be unethical, for example, for an oncologist to withhold information about proven care options such as radiation and chemotherapy from a patient with early-stage cancer. It is less clear, however, whether or not oncologists have the duty to inform their patients about early PC programs and services. It has been argued that oncologists have a moral duty to present hospice as an alternative to cancer therapy (Smith, 2011), but early PC interventions have never been discussed in this context.

Nonetheless, oncologists do have an ethical responsibility to provide their patients with any information that a reasonable person would want when considering whether or not to follow a physician's advice (CMA, 2004). Seeing as PC is known to benefit advanced cancer patients, it can be argued that a reasonable person would want to know about PC and how it can help them. Furthermore, involving a PC physician early on in the disease trajectory can actually be one of the best ways to promote patient autonomy. Early PC interventions have been shown to improve discussions about goals of care and increase the number of people who fill out advance directives (Temel et al., 2010; Gade et al., 2008; Rabow et al., 2004). By registering patient preferences and values in writing, advance directives support and extend autonomy in cases where a patient is no longer competent to make their own decisions (Emanuel et al., 1991).

In order to truly respect the principle of autonomy, the information provided to patients must also be free from "the entrenched values and goals of medical professionals" (Beauchamp & Childress, 2001). According to the College of Physicians and Surgeons of Ontario, this means that physicians should not restrict the information they share with patients on the basis of their own personal or religious beliefs:

Physicians must provide information about all clinical options that may be available or appropriate to meet patients' clinical needs or concerns. Physicians must not withhold information about the existence of any procedure or treatment because it conflicts with their conscience or religion. (College of Physicians and Surgeons of Ontario, 2015)

In the case of PC gatekeeping, this means that oncologists should not withhold PC as an option because of their personal values with regards to pursuing cure and avoiding death. The results of the MSR indicate, however, that the curative philosophy of care in oncology and the values and experiences of oncologists do appear to have an impact on their decision to refer patients to PC.

Although physicians are not entitled to impose their own personal views on patients, they are also not expected to surrender to their moral agency (Loewy, 1986). Healthcare workers have various values and beliefs and they should be permitted to express them (Pellegrino, 1986). Their personal values and beliefs often factor in to debates about late-term abortion or medical aid in dying, for example. To protect their moral agency and autonomy, physicians have the right to conscientiously object to provide these types of medical services on moral or religious grounds (Savulescu, 2006). Physicians are not permitted, however, to oppose the provision of care on the basis of their own preferences and comfort level (Savulescu, 2006). Furthermore, if a physician does object to providing a certain type of care, then they still have a ‘duty to refer’ the patient to someone who can (Cowley, 2017).

According to the results of the MSR, oncologists who choose to provide late PC referrals to patients choose to do so based on the preferences and values associated with their professional role, and not necessarily on moral or religious grounds. Some may argue that oncologists should keep their values out of the patient-physician encounter and be value-neutral, but value-neutrality is a concept that has been refuted by many prominent bioethicists who assert that important traits like empathy and compassion rely on the expression of values (Pellegrino, 2000; Beckwith & Peppin, 2000; Peppin, 1995). Rather, oncologists should be honest and disclose their values and preferences to patients and colleagues if they think it interferes with patient autonomy (Collège des médecins de Québec, 2018; CMA, 2004). The CMA Code of Ethics (2004) states: “Inform your patient when your personal values would influence the recommendation or practice of any medical procedure that the patient needs or wants.” In order to ensure that they are adhering to this ethical guideline, oncologists should examine their PC referral practices regularly to ensure they are not intentionally or unintentionally imposing their values on patients.



#### 4.3.4 Justice

The ethical issues surrounding oncologist-driven models of PC referral that become most apparent with the results of the MSR are issues related to justice. The principle of distributive justice in ethics demands that the benefits and burdens associated with medical interventions and treatment options be equitably distributed among patients (Beauchamp & Childress, 2001). This principle is also contained in the CMA's Code of Ethics (2004): "Recognize the responsibility of physicians to promote equitable access to health care resources". In order to achieve an equitable distribution of care, similar patients should have a fair opportunity to access a specific treatment or intervention (Beauchamp & Childress, 2001). The results of the MSR indicate, however, that oncologists have different beliefs about who should deliver PC and when PC referrals should be initiated. These different attitudes and perceptions toward PC lead to heterogeneous PC referral practices and results in variable access to PC services. The MSR contained in this thesis found, for example, that gynecologic oncologists report referring patients to PC less frequently because they perceive the provision of PC as part of their own professional role. Patients being treated for gynecologic cancers are therefore less likely to receive an early PC referral on account of the type of oncologist who is treating them.

According to Hui and Bruera (2016), this inequity in access to PC is a direct consequence of relying on oncologist-based models of PC referral. They argue that "access to palliative care is currently inequitable, owing to variable detection of [eligible] patients and differential thresholds for referral" (Hui & Bruera, 2016). They explain that in oncologist-based models of PC referral, patients are directed to different services and, thus, receive variable care depending on the PC expertise and referral preferences of their oncologist. Relying on oncologist-based models of PC referral also means that some patients will be better informed than others about the PC services

that are available to them. This puts some patients at an unfair disadvantage by restricting their ability to fully express their autonomy (Savulescu, 2006).

The exclusion of certain individuals or groups from early PC programs as a result of oncologist gatekeeping could therefore create an unfair distribution of the benefits of early PC, thereby violating the principle of justice. The quality of services that patients receive should not depend on the values or perceptions of the referring oncologist. Patients should not have to pick a specific oncologist in order to receive a service to which they are entitled. The inequity in PC access also extends to caregivers and family members who have been shown to benefit from PC interventions (Sun et al., 2015; Dionne-Odom et al., 2015; El-Jawahri et al., 2016). It also builds on the injustice that already exists in the field of PC, including the inequitable access to PC for patients living in rural or remote areas (Ahmed et al., 2004; Wood et al., 2004; Roscoe et al., 2006) and the inequitable access for patients in the United States, owing to the existence of the Medicare Hospice Benefit (Gordan, 1989).

#### **4.4 Discussion**

There are a number of ethical concerns associated with current oncologist-driven models of PC referral. As the *de facto* gatekeepers of PC, oncologists have an ethical responsibility to identify and assess the supportive care needs of patients and judge whether or not their needs merit a referral to PC. Adhering the principle of beneficence requires that oncologists provide patients with an early PC referral because of the proven benefits PC has been shown to have for advanced cancer patients. A lack of PC referral would only be ethically justifiable in situations where the oncologist is able to deliver specialty PC themselves or if the oncologist believes that referring a particular patient to PC would do harm more harm than good. Furthermore, early PC referrals support the ethical principle of non-maleficence by acting to reduce the harms typically

associated with the treatment of advanced cancer. It is less clear whether oncologists are required to provide early PC referrals under the principle of autonomy. Under the doctrine of informed consent, oncologists have an obligation to provide patients with any information a reasonable person would want when making a decision about their health, including treatment options and alternatives. Given the recent evidence supporting the benefits of early PC for advanced cancer patients, presenting PC as a care option seems justifiable. In addition, oncologists should not be withholding information about PC based on their personal values or beliefs in regard to pursuing cure or avoiding death. Oncologists have heterogeneous views of PC owing to the variety of their skills, knowledge and experiences working with PC experts. Should these perceptions be allowed to impact oncologists' referral decisions, it can create inequity in access to PC services, thereby violating the principle of distributive justice.

Overall, what this ethical analysis suggests is that PC gatekeeping by oncologists has the potential to violate certain ethical principles and professional codes of ethics if careful attention is not paid to the processes involved in identifying the supportive care needs of cancer patients and initiating referrals to PC. To my knowledge, this manuscript marks the first time that the ethics of early PC have been examined. Clinicians and scholars with ethical interests in the field of PC tend to focus their attention on the ethics of PC research (Casarett et al., 2000; de Raeye, 1994; Bruera, 1994), EOL care (Karnik & Kanekar, 2016) and physician-assisted suicide (Materstvedt et al., 2003; Beauchamp, 1996). As our interest in PC broaden, however, so too must our ethical inquiries in the field. Early PC is a relatively new approach to the provision care in oncology and we have yet to determine the ideal way to implement early PC services to best support the values and preferences of advanced cancer patients. Nonetheless, this ethical analysis reveals that the PC gatekeeping practices that are currently in place are not acting to promote the

best interests or autonomy of advanced cancer patients. Possible solutions to these ethical pitfalls include modifying oncologists' referral practices, empowering patients to speak up and ask for PC themselves, or implementing automated PC referral systems to augment existing gatekeeping practices or bypass them altogether. These options are discussed in the following section of this manuscript.

## **4.5 Implications**

### *Modifying the referral behavior of oncologists*

The variation in referral rates to specialist services is not new. For decades, studies have reported on the variation in referral rates mainly in the context of general practitioners' referrals to specialists (O'Donnell, 2000). Although the exact reasons for referral variations remain mostly unexplained, it is thought to be due, at least in part, to a lack of consensus among referring physicians about what constitutes an 'appropriate' referral to specialist care (O'Donnell, 2000). For physicians referring patients to specialist PC, this uncertainty is magnified by the fact that evidence supporting early PC has only emerged in recent years. What constitutes an appropriate referral to PC, in other words, is still an ongoing debate. Nonetheless, I have argued above that the current PC referral practices of oncologists are inappropriate, as they have the potential to violate the four principles of biomedical ethics. The most straightforward way to overcome the ethical issues is to modify the existing referral practices of oncologists to ensuring that they make appropriate and less varied use of available PC services to maximize benefits, reduce harm, support patient autonomy and improve the equitable provision of PC.

A small number of studies have attempted to modify the referral behavior of primary care practitioners, with the majority of studies being conducted in the UK (Akbari et al., 2008). Of the interventions attempting to change referral rates and increase referral appropriateness, those that

were most effective either involved the specialist consultants in intervention activities or relied on the active dissemination of evidence-based guidelines (Edwards et al., 2011; Akbari et al., 2008; McColl et al., 1994). In the context of PC, this could mean developing educational or peer review activities that bring together oncologists and PC experts. For example, oncologists could sit down and discuss their referral decisions with PC experts so that both parties can learn which patients are appropriate to refer to PC and which patients are not. In addition, modifying referral practices could be achieved by widely disseminating the evidence-based guidelines for early PC care published by the ASCO and the NCCN along with structured referral sheets.

#### *Automated palliative care referrals*

Alternatively, to address the ethical issues associated with oncologist-driven models of PC referral, referrals can be automated and generated based on a predefined set of criteria (Hui et al., 2018; Hui & Bruera, 2016). In automated-models of PC referral, patients who are admitted to the hospital would be routinely screened in order to identify those who have unmet supportive care needs. If a patient meets the predefined criteria, the computer would generate an automatic referral to PC. Referrals can be based on a variety of factors including the patient's diagnosis and prognosis as well as their physical and psychosocial needs, goals of care, and caregiver concerns (Hui et al., 2018; Weissman & Meier., 2011; Glare et al., 2013).

Despite the increasing interest in automated models of PC referral, these models have only scarcely been tested in practice. Rocque et al. (2015) found, for example, that automated PC consults increased the PC referral rates at their academic medical center from 12% to 60%. The intervention also improved patients' understanding of their diagnosis and was viewed favorably by 74% of oncologists (Rocque et al., 2015). Similarly, Adelson et al. (2017) found that triggered referrals increased PC consultations in their hospital from 39% to 80%, led to a reduction in 30-

day hospital readmission rate, and significantly increased the rate of hospice referral. In another study, Einstein et al. (2017) found that cancer patients receiving automatic PC referrals consulted with outpatient PC services earlier and more frequently than controls. Although the overall rate of hospice referral stayed the same, Einstein et al. (2017) found that patients with triggered PC referrals stayed in hospice twice as long as patients referred by their primary oncologist.

There is uncertainty about whether automated referrals should be used in parallel or in conjunction with oncologist-driven models of PC referral. In parallel models, the automated PC referrals would be provided independently of the oncologists' own referrals. A computer would generate a referral for any patient meeting the referral criteria that has not already been referred by the oncologist (Hui et al., 2018). In an augmented model of PC referral, automated referrals would be used to improve oncologists' judgement by electronically prompting them to provide a PC referral to a patient who meets the predefined criteria (Hui et al., 2018). This referral model however, would still rely on the oncologist as a gatekeeper. Recently, Hui et al. (2018) surveyed sixty international experts to determine which model of PC referral they preferred. The majority of members on the panel (86%) agreed that PC referrals should be based on automatic and clinician-based referrals. Only 18% of panelists felt that PC referrals should be clinician-based alone, and only 7% thought that referrals should be completely automated. Most of the experts agreed that automatic referrals can increase referral rate and facilitate earlier access to PC, but some experts were concerned that automated referrals might create animosity between patients and clinicians, as patients might feel "forced" into a PC consult (Hui et al, 2018).

The consensus seems to be that automated PC referrals should be used to enhance the gatekeeping power of oncologist, not to override it. Automated models of PC referrals will likely be most useful to oncologists who choose to refer the majority of their patients to PC, but these

models can also be used to bypass the referral practices of oncologists who tend to delay PC discussions. This system can standardize PC referral practices and help overcome the inequity that currently exists under oncologist-driven models of PC referral. The potential for automated referral systems depends, however, on the existing infrastructure and resources available (Hui et al., 2018; Hui & Bruera, 2016). An automated referral system should be able to adjust depending on the volume of patients requiring PC and the amount of resources available within a particular institution (Hui & Bruera, 2016). In situations where resources are limited, automated referrals can help oncologists determine who is most in need of a PC consultation (Hui & Bruera, 2016).

### *Empowering patients*

A third way to facilitate ethical practices when it comes to PC gatekeeping could be to empower patients and encourage them to ask their oncologist for a referral to PC services. One of the potential ethical issues outlined above is that, by only discussing PC near the end of life, oncologists are not providing patients with all beneficial care options and thereby are restricting their autonomy. Patient empowerment, defined by the WHO as “a process through which people gain greater control over decisions and actions affecting their health” (Nutbeam, 1998), can help advanced cancer patients gain knowledge and confidence with respect to their supportive care needs so they are better able to recognize when these needs are not being met by the oncologist.

Empowerment has become an important concept in cancer care, with a number of review articles being published on the topic in past few years (Jorgensen et al., 2018; Eskildsen et al., 2017; Boveldt et al., 2014). Bakitas et al.'s (2009) even included patient empowerment as a component of their Project ENABLE RCT investigating the effectiveness of early PC. During planned psycho-educational sessions, nurses aimed to empower patients in broaching PC and EOL care with their physician. Although patients receiving the intervention had improved QOL

and mood, it is unclear whether these benefits can be attributed to the patient empowerment component of the program. Furthermore, Schenker et al.(2014) found that while cancer patients with unmet supportive care needs are more likely to recognize the need for a PC referral, they are not more likely to request it. According to Schenker et al. (2014), the beneficial effects of patient empowerment can be diminished by the power imbalances that are inherent to the doctor–patient relationship. Further research needs to be done to determine whether or not patient empowerment or other patient-centered approaches can increase the appropriate use of PC services.

#### **4.6 Limitations**

There are a number of limitations that apply to this ethical analysis. First, principlism, the ethical framework guiding this manuscript, is an ethical theory that is not without its weaknesses. Clouser and Gert (1990) are two of the biggest critics of the four principles approach and argue that although the principles embody key concerns, they do not tell an agent how to act. They write that principlism lacks a “single, clear, coherent, and comprehensive decision procedure for arriving at answers” (Clouser & Gert, 1990). The principle of justice, for example, might tell a physician to be conscious of the way she distributes resources but it does not propose solutions about *how* to distribute them. Another common criticism of principlism is that it does not offer a solution to situations where the ethical principles are in conflict with one another (DeGrazia, 1992). Beauchamp and Childress have addressed this concern, however, by elaborating on how the principles are further specified and judgements justified (Beauchamp & Childress, 2001).

Second, principlism is only one of many different ethical approaches that can be used to analyze of the ethics of PC gatekeeping including feminist ethics, virtue ethics and deontological ethics. These ethical approaches are often in conflict with one another and, therefore, if an ethical approach other than principlism was used to analyze PC gatekeeping, then the conclusions of this



manuscript might have been different. Particularly applicable to the topic of PC gatekeeping is communitarian ethics. Communitarianism is an ethical perspective that views individuals as members of society and shifts the attention away from individual rights and duties and towards the responsibilities of groups or communities (Callahan, 2003). In other words, a communitarian philosopher might choose to examine how early PC is judged by various groups (eg. oncologists, patients, PC physicians, etc.) or how the current models of PC referral impact society as a whole. This manuscript, however, is only meant to serve as a first step in the analysis of the ethics of PC gatekeeping. It is beyond the scope of this thesis to review the application of each ethical theory to the topic of PC gatekeeping. Other ethical approaches, however, can and should be applied to early PC care in future investigations.

#### **4.7 Conclusion**

For patients diagnosed with advanced cancer, the introduction of PC can help to promote their best interest, mitigate the harms of anticancer therapies and support their right to autonomy. It follows then, that when oncologists are faced with a decision about whether or not to refer a patient to PC, the ethical response would be to refer that patient if their supportive care needs are not already met. Under the current oncologist-driven models of PC referral, however, this is not the case. Oncologists are often basing their decisions to refer on their own personal values and experiences with PC, thus creating an unfair distribution of the benefits of PC services. Solutions to this problem include modifying oncologists' referral practices, enhancing their gatekeeping role using automated methods of referral or empowering patients to request a referral from their oncologist. Given that the evidence supporting early PC interventions is relatively new, limited literature exists about the ethics of early PC referral. Therefore, this manuscript acts as a starting point for more comprehensive evaluations of the ethics of PC gatekeeping in oncology.

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## **Chapter 5 – General Discussion**

### **5.1 Summary & contribution to knowledge**

The definition of palliative care has changed considerably since the term was first coined by Balfour Mount in 1976. What began as an approach to care reserved for terminally ill cancer patients has transformed into a type of care suitable for anyone dealing with a life-threatening illness. Recent evidence has shown that, in patients with advanced cancer, introducing PC soon after diagnosis can significantly improve a number of patient and caregiver outcomes including quality of life, satisfaction with care and mood. Despite recent clinical practice guidelines now recommending that PC be introduced within 8 weeks of diagnosis, oncologists continue to refer patients only in the late, terminal stages of the illness trajectory. Although the delays in PC referrals have been attributed to multiple factors, policy makers have focused their efforts primarily on overcoming the system-level barriers to referral such as the lack of PC service availability and the small PC workforce. Research has also shown, however, that PC delays exist even when oncologists acknowledge that they have access to these services. Improving the appropriate delivery of PC services will thus necessitate a better understanding of the barriers existing at the level of the referring oncologists.

Although the perceptions and attitudes of oncologists toward PC are well documented in the literature, no article has attempted to summarize these perceptions nor has a study examined the appropriateness of current models of PC referral. This thesis addresses these knowledge gaps by systematically reviewing the literature investigating oncologists' perceptions of and attitudes toward PC as well as critically analyzing oncologist-driven model of PC referral from an ethical perspective. These investigations were carried out and presented as two separate manuscripts.



The systematic mixed studies review contained in Manuscript 1 found that the results of the literature investigating oncologists' perceptions of PC could be divided into six main themes: 1) the value of PC, 2) the timing of PC referral, 3) the role of the PC provider, 4) coordination of care, 5) philosophy of care, and 6) the impact of PC referral on the patient. The results found that although most oncologists perceive PC as a useful adjunct to standard oncology care, they have vastly different opinions about who should deliver PC and when PC referrals should be initiated. The results also indicate that oncologists are concerned about sharing roles and responsibilities with the PC team, consolidating the philosophies of oncology and PC, and causing emotional distress to patients. Overall, the results of this systematic review demonstrate that oncologists' perceptions of PC vary greatly and seem to depend not only on their knowledge of PC, as is often suggested in the literature, but also on their professional culture and identity.

Manuscript 2 contains an ethical analysis of the PC gatekeeping practices of oncologists and concludes that current oncologist-driven models of PC referral have the potential to violate certain ethical principles if not carried out appropriately. By withholding referrals from patients until the terminal stages of disease, oncologists are effectively preventing patients from gaining valuable benefits from early PC programs. By providing earlier referrals to PC, oncologists are not only offering these benefits to patients but they are also acting to reduce harm in accordance with the principle of non-maleficence and supporting a patient's right to be fully informed about their care options in accordance with the principle of autonomy. Furthermore, the individual PC referral practices of oncologists vary greatly under the current PC referral models owing to their heterogeneous perceptions of PC. This creates inequity in access to PC services and means that certain patients who could benefit from PC will not have access to early PC services by virtue of the identity of the oncologist who is in charge of their treatment.

The research carried out for the purpose of this Master's thesis adds to the growing body of literature on palliative and end-of-life care. Since 1993, the number of articles published on the topic of hospice care has grown exponentially (Chang et al., 2016; McIlfatrick & Murphy, 2013). Particular growth in hospice research has taken place over the last 10-15 years, likely due to the WHO's (2018) recognition of PC's contributions to health, developments in mapping the global levels of PC development (WHO, 2014) and significant investments in PC research initiatives in the US, Europe, Canada and Australia (Gelfman et al., 2013; Canadian Cancer Research Alliance, 2011). PC research is not only expanding in volume, but also in scope as an increasing amount of research is being conducted on the benefits of PC services for patients with non-cancer conditions such as heart disease (Adler et al., 2009), dementia (van der Steen et al., 2014), chronic obstructive pulmonary disease (Curtis, 2008), and HIV/AIDS (Harding et al., 2005). By expanding PC studies to non-cancer patients, researchers are not only addressing the inequity that currently exists within these particular medical specialties, but between the different specialties as well.

Additionally, the results of this research project can be used to benefit the field of family medicine by shedding light on the interface between primary care, palliative care and oncology. Currently, in Canada, family physicians are the most frequent providers of palliative medicine in every province. Up until recently, palliative medicine was not considered an established medical specialty in the country, meaning that Canadians were typically required to seek supportive care services from their primary care providers. Since patients requiring early PC are usually complex and require both active treatment and PC, providing the best possible care to these patients will require that family physicians and oncologists work together. By investigating the link between oncology and PC, this research project can help identify potential areas of conflict that might

arise when health professionals from both groups try to collaborate. Moreover, this work builds on literature investigating the relationship between generalist and specialist physicians (Piterman & Koritsas, 2005; Marshall & Phillips, 1999; Pearson, 1999). Although the partnership between generalist and specialist PC providers has been explored (Gardiner et al., 2012), this thesis serves as a first inquiry into the relationship between physician-providers of PC and cancer specialists.

The results outlined in both manuscripts can also be used to inform the development of new models of shared care between family physicians, PC specialists and oncologists. Although the PC models that currently exist (eg. Hawley, 2014; CHPCA, 2013) highlight the importance of introducing PC early, they do not specify who is responsible for initiating PC referrals nor do they describe the roles of the various physician groups once a referral has been initiated. Based on the results of this thesis work, designing an appropriate model of early PC delivery requires that the oncologist be recognized as an important healthcare gatekeeper, a role typically reserved for physicians working in primary care. In addition, new PC models could see family physicians being placed in a unique consultative role owing to their growing knowledge and skills in PC.

Furthermore, this thesis adds to a growing body of literature on the ethics of PC. When it comes to the ethics of PC, popular topics often debated in the ethics community are the ethics of PC research (Casarett et al., 2000; de Raeve, 1994; Bruera, 1994), EOL care (Karnik & Kanekar, 2016) and physician-assisted suicide (Materstvedt et al., 2003; Beauchamp, 1996). The ethical concerns often discussed in the context of PC research are the vulnerability of dying patients, the difficulty of obtaining informed consent and the potential for increasing distress in patients and families (Casarett et al., 2000). Similar concerns are raised when discussing the ethics of EOL care, in addition to issues related to EOL decision-making, the rationing of futile treatments and the costs associated with the provision of EOL care (Karnik & Kanekar, 2016).

One of the most controversial topics in EOL care at the moment however, particularly in Canada, is medical assistance in dying (MAID). MAID provides patients who are suffering from a terminal or intolerable illness the option of ending their life with the assistance of a physician or nurse practitioner (Government of Canada, 2018). The physician or nurse practitioner either directly administers a substance that causes death or prescribes a drug to the patient so they are able to bring about death themselves (Government of Canada, 2018). MAID was legalized in Quebec on June 5, 2014 (Hivon & Bill, 2014) and became legal across the entire country two years later, in June 2016 (*An Act to amend the Criminal Code and to make related amendments to other Acts, 2016*). Discussing whether or not MAID is appropriate or ethical is beyond the scope of this thesis, however, MAID is important to mention here because of the implications it has for PC. With MAID now being a reasonable option for patients suffering from an advanced illness, it is more important than ever to ensure that patients have appropriate access to quality PC services as an alternative. MAID should be a choice and patients should not feel compelled to turn toward MAID because of the deficiencies in our PC referral systems or delivery models.

## **5.2 Future directions**

Future research and policy is needed to overcome the PC referral barriers that currently exist in oncology. In order to better understand how the professional culture and identity of the oncologists are affecting their PC referral practices and collaboration with PC physicians, the professional subcultures of oncology and PC need to be accurately described and the conflicts between the two cultures need to be examined. In addition, more research is needed to describe the perceptions of PC from the perspectives of the PC physicians. The majority of research projects investigating the perceptions of PC in oncology have focused on describing the views of patients, caregivers or members of oncology team, with little attention being paid to the PC

physicians themselves. Asking PC physicians about their experiences delivering PC and their views on the barriers and facilitators to early PC referral can help to pinpoint the areas of care where oncologists and PC physicians disagree. Ideally, future research should investigate the views of both physician groups and compare them. Seeing as family physicians are the most frequent providers of PC in Canada, future research should also examine the perceptions and attitudes of primary care providers towards PC. Furthermore, new studies should examine the PC perceptions of specialists working in other fields of medicine such as neurology, cardiology and emergency medicine. Further research in these areas could help to corroborate the findings of this thesis by demonstrating the impact different professional cultures can have on PC attitudes, perceptions and referral practices.

It is also important that we continue to expand and improve existing PC programs across the globe. The arguments outlined in this thesis depend on the assumption that advanced cancer patients have access to PC services. If we hope to encourage oncologists to provide patients with early referrals to PC, then ensuring PC service quality and availability is a necessary prerequisite. As the availability of PC services increases, the spotlight can be turned towards the gatekeepers of PC who are tasked with making appropriate use of the available resources. New policies and programs should be developed to support and educate physician gatekeepers about PC and help future gatekeepers develop professional identities that allow them to collaborate effectively with PC providers. Additional work should also be done to study the feasibility and performance of automated referral systems to help enhance the PC gatekeeping practices of oncologists.

### **5.3 Conclusion**

Advanced cancer patients often have physical and psychosocial symptoms that cannot be managed by the oncology team alone. Research has demonstrated that early referrals to specialist

PC can help manage these symptoms, but most patients are only referred in the last few weeks of life and some patients are never referred at all. This thesis examined oncologist-driven models of PC referral in order to expand our knowledge of the physician-level barriers to early referral. As the number of people diagnosed with cancer continues to increase, addressing these barriers is becoming a matter of primary concern. The findings contained in this thesis can be used to inform the development of strategies to improve the early delivery of PC to ultimately enhance the quality of life of patients and family members dealing with an advanced cancer diagnosis.

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