

# A systematic review on the Palliative Care model towards the advance cancer patients

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*Abstract— There is a limited literature of patient perspectives on the role of their physicians in the provision of palliative care. As such, much of the published literature comprises of small, exploratory single-site studies conducted in urban centers. The limited number of studies published about cancer patients' perspectives on roles of physicians in their palliative care, means that there are many gaps in our knowledge. These gaps may be exacerbated by the methodological and design limitations in the studies reviewed here. The aim of this study is to help close the gap in the literature, by further examining the perspectives of patients with advanced cancer, on the role their physician can play in their palliative care. This study will not only examine patient-stated barriers to palliative care provided by their physician but will also examine the frequency and nature of care by patients' physicians, and determine the provision of, and preferences for, general, palliative, and supportive care for patients by different practitioners.*

*Keywords: Systematic review, Palliative Care model, cancer patients.*

## 1. Introduction

Modern palliative care models arose from Dame Cicely Saunders and the British Hospice Movement in the 1960s, in an attempt to care for the cancer patient and his or her at the end of life, with an interdisciplinary team (Glare & Clarke, 2002; Hui & Bruera, 2016; Loscalzo, 2008). Dame Saunders founded St. Christopher's Hospice in London in 1967 (National Hospice and Palliative Care Organization, 2016). Subsequently, in 1969, Swiss-American psychiatrist Elisabeth Kübler-Ross published "On Death and Dying," delineating her theory of the five stages of grief.

## 2 Literature review on Palliative Care

According to the World Health Organization (WHO), palliative care "is an approach that improves the quality of life of patients facing the problem associated with life-threatening illness" (World Health Organization, 2017). Specifically, the WHO states that quality of life is improved "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."

Furthermore, according to the WHO, palliative care performs the following functions:

- "provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

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

There are varying inclusion criteria considered when determining a patient's palliative care needs; these can include prognosis, the changing of patient choice or decisions, a patient's clinical indicators, and the intensity of care required (H. Mitchell et al., 2015).

Both in the literature and in society at large, the terms and definitions surrounding palliative care are vague and undefined; the terms 'palliative care,' 'supportive care,' 'advanced care,' 'terminal care,' and 'end-of-life care' are not clearly delineated and often used interchangeably in the

literature. Studies varied on their definitions of "palliative" of "terminal" care on the basis of prognosis, supportive measures, and other inclusion or exclusion criteria. For instance, one definition of palliative care included having a do-not-resuscitate order (DNR), while another specified that patients were eligible for palliative care if they had a prognosis of three months or less (Michiels et al., 2007; Peng et al., 2009). This difference shows that the terms used in this literature have unclear distinctions between them, with varying definitions.

In almost all definitions, however, palliative care includes end-of-life care, which is a rapidly growing public health issue in the 21<sup>st</sup> century, particularly as technological advances allow for a prolonged life and, a prolonged death (Rao, Anderson, & Smith, 2002). In addition, palliative care offers care not only to the patient, but to their families and caregivers as well (Davies & Higginson, 2004).

It is pertinent to note that the term palliative care may carry stigma for patients, potentially becoming a barrier for patients to enroll in or stay involved with palliative care (Zimmermann et al., 2016). Practitioners also cite stigma of the term as a barrier to referral of patients to palliative care (N. Fadul et al., 2009; Rhondali, Burt, Wittenberg-Lyles, Bruera, & Dalal, 2013). Several possible solutions have been proposed,

including a change in the name, public education, information for patients, and education for healthcare providers (Dalal et al., 2011; Maciasz et al., 2013; Zimmermann et al., 2016). Another possible approach may be an emphasis on symptom control, which may make palliative care services more accessible (Malani & Widera, 2016). At the Princess Margaret Cancer Centre, for instance, the clinic is called the "Outpatient Oncology Palliative Care and Symptom Control Clinic."

Overall, the multidisciplinary nature of palliative care "enables the multidimensional care needs of patients to be addressed" (Hui & Bruera, 2016).

### 2.1 Palliative Care Specialists

Physicians are not presently required to hold official qualification to be considered palliative care specialists. However, 88% of sub/specialists in palliative care, and 75% of physicians primarily practicing palliative care, reported having completed additional training, including non-accredited training, in the field (Society of Palliative Care Physicians (SPCP) Human Resources Committee, 2015). Two formal qualifications have been established recently: a Year of Added Competence certificate, and a subspecialty qualification which will begin training of its first cohort of residents in July 2017.

The new Royal College of Physicians and Surgeons' subspecialty training program in palliative medicine also educates clinicians in these areas, which leads to greater levels of expertise. Even palliative care specialists without accredited training, however, may be able to provide more expertise than a physician with a general practice, as they have a focused practice in palliative care, thus are likely to have more exposure to the array of issues patients with advanced illness face, and therefore more expertise.

The provision of palliative care can be seen as having three levels: primary, secondary, and tertiary. Primary palliative care is performed by clinicians who are not specialists in palliative care; this can include physicians and oncologists. Secondary palliative care involves palliative care specialists as consultants in care; in tertiary palliative care, the palliative medicine specialist is the most responsible physician (Hui & Bruera, 2016). All three levels of palliative care can work together to ensure all patients can get adequate access to palliative care.

In developed nations, tertiary palliative care, in the form of specialist palliative care teams, has become a common model of providing palliative care. Often situated in hospitals (in both in-patient and out-patient clinics) or in a community-based practices, they allow teams of specialists, nurses, and allied healthcare workers to work together to improve the quality of life of patients needing palliative care. The utilization of such a structure has been shown to improve care for patients, including in pain and symptom control, improve patients' likelihood of achieving their preferred place of death, reducing cost, and improving patient satisfaction of care (Davies & Higginson, 2004; Hearn & Higginson, 1998; Higginson et al., 2002). The longitudinal nature of this care, furthermore, as opposed to one-time consultations, increases its effectiveness (Hui & Bruera, 2016).

Palliative care teams are not always easily accessible. This may be especially true for patients: with a low socioeconomic status, who may have less access to medical care in general, and greater environmental barriers to accessing care; of minority cultural and ethnic groups, who may not be able to access culturally relevant resources in their language, or who may be missed altogether; and, older individuals, in whom symptoms are often under-assessed and undertreated (Davies & Higginson, 2004).

Palliative care specialists share many of the same philosophies as other specialties, including physicians in general practice, geriatric medicine, paediatrics, psychiatry, and rehabilitation; holistic care being a cornerstone in these practices (Davies & Higginson, 2004). These specialists are also often attuned to the wider needs their patients might face, including the needs of their families and caretakers.

Beyond the training of specialists, palliative care (and particularly early palliative care) may benefit from more education of other healthcare practitioners, including other physicians. This will lead to a greater understanding of the importance of palliative care in improving patient quality of life and ultimately, more provision of palliative care earlier in the disease trajectory (Davies & Higginson, 2004). Textbooks for health professionals, including future physicians and nurses, rarely contain information on palliative care, nor do many

medical school curriculums include palliative care as an area of focus, though it has been found that palliative care training is found to be valuable by trainees (Parikh, White, Buckingham, & Tchorz, 2017). The same study also found that only 6% of their residents had completed a core palliative care rotation through their post-graduate education. Education of the public may also be an important component of increasing understanding of what palliative care is (Davies & Higginson, 2004).

### 2.3 Palliative Care in Cancer

Historically, palliative care was developed in cancer populations (Glare & Clarke, 2002). Perhaps because of this, patients with cancer are the most common users of palliative care services, and are more likely to receive these services than patients with other life-limiting conditions (Pivodic et al., 2013). Furthermore, higher proportions of palliative care usage in cancer populations is exacerbated by the fact that prognosis in non-malignant diseases is less uniform (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), though disease-specific predictors for dementia, congestive heart failure, chronic obstructive pulmonary disease, and other diseases, have been identified (Coventry, Grande, Richards, & Todd, 2005). Thus, it may be harder to identify the ideal time to refer non-cancer patients to palliative care services.

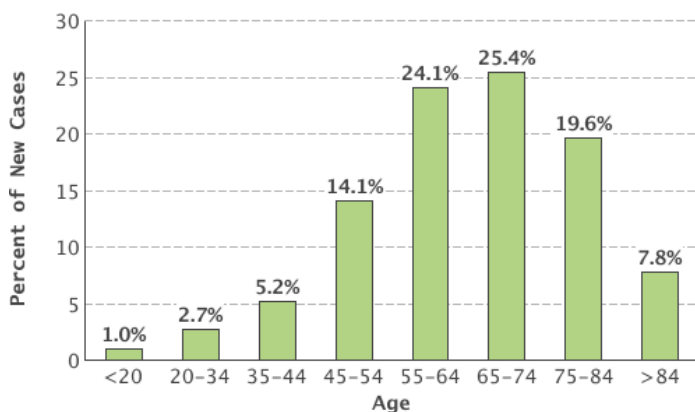
Even for patients with cancer, however, referral to palliative care services is often late or does not occur. For instance, in a 2012 MD Anderson study, only 45% of patients with cancer had a

consultation with palliative care services, with the first consultation only 1.4 months before death (Hui et al., 2012). Moreover, patients with different malignancies may be referred to palliative care services at different rates, despite similar symptom burdens or other needs that can be addressed by palliative care teams (N. A. Fadul, Osta, Dalal, Poulter, & Bruera, 2008).

Patients with cancer are an important palliative care population because, as Aabom and Pfeiffer write, they have "increasing unmet psychosocial needs as disease [progresses]" (2009).

Overall, palliative and supportive care needs will continue to grow as the population ages globally<sup>1</sup> (Davies & Higginson,

2004). This is particularly true for cancer patients, as advancing age itself is the strongest risk factor for cancer, as illustrated in Figure 1 (“Risk Factors: Age - National Cancer Institute,” 2015; Rodin, 2016). Longer life expectancies have increased the number of new cancer cases year over year, even while the incidence rate of cancer has remained constant (Cancer Society’s Advisory Committee on Cancer Statistics, 2016). Thus as populations get older, and technologies continue to improve, more people will be living with cancer for longer periods of time, including those with advanced cancer. These populations will need more palliative care services than ever before.

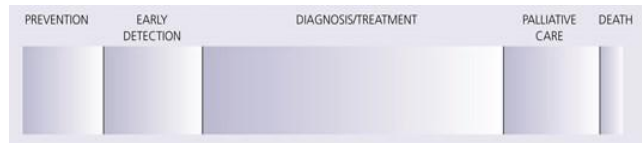


**Figure 1** Percentage of new cancers by age group: all cancer sites.

### 2.4 Early Palliative Care

Palliative care provided early in the disease trajectory is increasingly endorsed as a model of care that can improve quality of life, mood, satisfaction with care, and even survival, for patients with advanced cancer (Bakitas et al., 2009; Temel et al., 2010; Zimmermann et al., 2014).

Historically, patients were ‘transferred’ to palliative care services (either specialists or the physician) only when it was felt that there were no more life-prolonging treatment options to pursue; there was a distinction between curative and palliative care (Glare & Clarke, 2002; S. Murray, Kendall, K, & Sheikh, 2005). In this model, patients are referred late in their disease course, which may limit the ability of providers to alleviate psychosocial suffering and build relationships with patients (Figure 2).



**Figure 2** Sequential model of palliative care.

There is a distinction between curative and palliative care; patients are referred to palliative care services only when there are no further life-prolonging treatments to offer.

Since the 1980s, however, practices have shifted towards providing palliative care alongside curative treatment, as illustrated in Figure 3. Physicians have begun to recognize that palliative care is not needed only just before death; rather, palliative care can improve quality of life long before a patient approaches death: concurrently with treatment or even at the time of diagnosis (Davies & Higginson, 2004). This model may be especially effective for places where specialist palliative care teams are available (Glare & Clarke, 2002).

Overall, this model bears similarities to the first model, as curative and palliative care is conducted by distinct teams. However, palliative care is provided earlier. Across the globe, the early provision of palliative care is becoming the new standard in care. Nations with advanced integration of palliative care include the U.S., Australia, and Japan, there are 500 hospice-palliative care services, meaning there is 1 service for every 67,000 people (Lynch, Connor, & Clark, 2013). U.S., thus ranks fourth in the world for number of palliative services, ranking only after Bermuda, the United States, and the Cayman Islands (the first and last of which have very small populations).

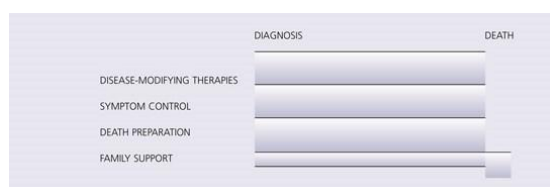
Early palliative care is facilitated by outpatient clinics, particularly for ambulatory patients who are already visiting the oncologist; the outpatient model can also accommodate greater volumes of patients (Dalal et al., 2011). In addition to outpatient clinics, having hospital-based consultation teams, palliative care wards, community-based provision of primary palliative care, and home-based care are all key components of an integrated palliative care model that can effectively cover patients in all stages of disease (Hui & Bruera, 2016).



**Figure 3** Concurrent model of palliative care. Palliative care is provided alongside curative treatment (Glare & Clarke, 2002).

Early palliative care that is integrated with curative treatment must become the standard of care, to which patients have a right (Davies & Higginson, 2004; Malani&Widera, 2016). It has even been suggested that with greater integration, “palliative care would no longer be chosen; it would simply be integrated into comprehensive oncology treatment that supports patients and caregivers by incorporating palliative care principles and services into all aspects of their care” (Caprio, 2016).

Glare and Clarke suggest a future of mixed management, where curative and palliative care freely mix (2002; Figure 4). This approach, to be achieved by educating all health care professionals to provide supportive care services, symptom control, and advance care planning, may provide several advantages, they argue, including quality-of-life focused treatment throughout the disease course for all patients. As Nancy Merrow writes, “[w]hen palliative care becomes invisible because it is completely ubiquitous in our practices and the system, our mission will have been achieved (Merrow, 2016).



**Figure 4** Mixed management model of palliative care.

Unfortunately, this model seems unrealistic at present, particularly with already low levels of education in palliative and supportive care amongst health care trainees. Furthermore, palliative care is a highly specialized discipline, and specialists have expertise in symptom control, pain management, and other supportive care aspects, all of which require a higher level of training not all practitioners can achieve. As Hui and Bruera write, it would be “unreasonable” to expect oncologists

to be able to attend to all palliative and supportive care needs of their patients in addition to their other responsibilities; moreover, oncologists might face other barriers than expertise to providing this care, including limited time, experience, access to resources, as well as variable levels of interest in providing this care (2006). Thus, having specialist palliative care, alongside oncologists and physicians who can provide primary palliative care, is the current ideal model for the provision of palliative care.

Furthermore, the scope of palliative care has increased, to not only helping with disease-related symptoms, but also psychosocial care, planning for the future, and caregiver support (Addington- Hall, 2002). It has even be suggested that palliative care may be helpful for patients with

potentially-curable diseases (Malani&Widera, 2016). Thus, the current, concurrent model of palliative care seems ideal for providing effective, and early, palliative care.

#### Effectiveness of Early Palliative Care

Palliative care provided early in the illness trajectory, for patients with advanced cancer, has been shown to improve quality of life, symptoms, satisfaction with care, and even survival.

In a 2014 randomized control trial (RCT) of patients with advanced cancer, Zimmermann et al. showed significantly better quality of life, satisfaction with care, and symptom severity for patients receiving regular palliative care consultations, as compared to a control group (Zimmermann et al., 2014).

The group cluster-randomized 24 oncology clinics into an intervention arm with a minimum of monthly palliative care clinic visits, and a usual-care arm, stratified by size of clinic and tumour site. Patients (n=461) were eligible if they had a diagnosis of advanced cancer, a European Cooperative Oncology Group (ECOG) performance status of less than three, and a prognosis of 6-24 months.

The primary endpoint, a change in the score for quality of life (measured by the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being, or FACIT-Sp) at three months showed better outcomes for the intervention arm but was statistically insignificant; at three months, however, quality of

life was significantly better for the early palliative-care arm as measured by the Quality of Life at the End of Life scale, or QUAL-E), as was satisfaction with care (measured by FAMCARE-P16).

Other secondary outcomes, measured at four months, included quality of life (measured by the FACIT-Sp and QUAL-E), satisfaction with care (measured by FAMCARE-P16), and symptom severity (measured by the Edmonton Symptom Assessment System, or ESAS), and were all significantly more favorable for patients in the intervention arm.

Similarly, Temel et al.'s 2010 study found improved outcomes for patients in the early palliative care arm compared to a control arm, for quality of life and mood (Temel et al., 2010). The paper also reported better survival, more documentation of resuscitation preferences, and less aggressiveness of treatment in the interventional arm, from post-hoc tests.

In this non-blinded patient-randomized trial of patients with newly diagnosed metastatic, non-small-cell lung cancer, 151 patients were randomized either to an early palliative care arm with at minimum monthly palliative care visits, or a usual care arm. Patients were eligible if they had a new diagnosis (within eight weeks) of non-small-cell lung cancer, and an ECOG status of less than 3.

The primary outcome was health-related quality of life (measured by a change in Trial Outcome Index score, or TOI; a sum of the scores on the Functional Assessment of Cancer Therapy-Lung scale, or FACT-L, and the Lung-Cancer Subscale, or LCS, of FACT-L) at 12 weeks from baseline, and was statistically significantly different, favoring the palliative care arm.

Secondary outcomes included mood, assessed by both the Hospital Anxiety and Depression Scale (HADS), and the Patient Health Questionnaire 9 (PHQ-9) at 12 weeks. Intervention arm patients performed significantly better with respect to mood when compared to patients in the control arm. The study team also found in post-hoc tests that the patients in the early palliative care arm received significantly less aggressive treatment, were significantly more likely to have resuscitation preferences documented, and had longer survival

than those in usual care. This single-site study was conducted at a tertiary, urban hospital in Boston, Massachusetts, USA.

Finally, a 2009 paper of a randomized control trial of a palliative care intervention in patients with advanced cancer, by Bakitas et al., reported improved quality of life and mood in patients receiving palliative care services (Bakitas et al., 2009). Post-hoc tests also showed longer survival for patients in the intervention arm, which was statistically insignificant.

In this patient-randomized trial, patients were eligible if they had a new diagnosis (8-12 weeks prior) of life-limiting cancer with prognosis of approximately one year. Patients had to be without impaired cognition, an Axis I psychiatric disorder, or active substance use. One caregiver per patient was asked to participate in the study, but a lack of caregiver participation was not an exclusion criterion. Patients were randomly assigned (stratified by disease) into a usual care arm, or an interventional arm that included psychoeducation over four weeks, as well as monthly telephone follow-ups, by advanced practice nurses.

Primary outcomes were quality of life (measured by the Functional Assessment of Chronic Illness Therapy for Palliative Care), symptom intensity (measured by the ESAS), and use of resources (measured by electronic medical recorded number of days in hospital, number of days in the intensive care unit, and number of emergency department visits). Patients in the intervention arm showed significantly better outcomes for quality of life, as well as lower, but statistically insignificant, symptom intensity in longitudinal intention-to-treat analyses. There was no significant difference in resource use between intervention arms.

Mood (measured the Center for Epidemiological Studies Depression Scale, or CES-D) was a secondary outcome, and was shown to be significantly better for patients randomized into the palliative care arm. Participants were recruited from two sites, a cancer centre and aveterans' hospital, in rural New Hampshire, USA.

Relatively few patients in usual-care arms of these landmark RCTs were referred to palliative care, indicating that, at the time of data collection, there needed be greater integration of palliative care services, and perhaps more access to secondary and tertiary palliative care (Hui&Bruera, 2016).

Other studies since these have also shown the effectiveness of early palliative care. For instance, in a 2016 non-blinded randomized clinical trial of 160 adults with hematologic malignancies undergoing hematopoietic stem cell transplantation, subjects were assigned to either the intervention arm of twice-weekly symptom-based inpatient palliative care consultation, or a control arm who could see palliative care clinicians upon request (El-Jawahri et al., 2016). The study found that those in the intervention arm reported less decline in quality of life when compared to the control arm ( $p=0.045$ ). Secondary outcomes included anxiety, increase in depression, difference in fatigue, and symptom burden, of which intervention arm patients had significantly more favorable outcomes in all outcomes at week 2 from baseline, and in quality of life and increase in depression at 3 months.

### 2.5 Palliative Care in Medicine

Physicians can be a valuable resource for patients with advanced cancer in palliative care, and can help improve the quality of life in these patients (Rubin et al., 2015). According to Cancer Care Ontario's GTA 2014 Cancer Report, one-half of patients with cancer would benefit from palliative care services (Cancer Care Ontario, 2004), particularly as a majority of patients with cancer experience pain and symptoms from their disease or the treatment of the disease (Ashbury, Findlay, Reynolds, & Mckerracher, 1998). Both palliative care specialists and physicians can work together to ameliorate patient experiences with their disease.

The importance of primary care physicians becomes clear as we consider that, even as early palliative care has become increasingly endorsed as a model of care that can help improve quality of life (Zimmermann et al., 2014), specialized palliative care services continue to be found mostly in urban areas in developed nations (G. K. Mitchell, Burrige, Colquist, & Love, 2012). Furthermore, large numbers of the population may benefit from palliative care; in western Australia, as many as 0.28%-0.50% of the population were identified as being potentially able to benefit from palliative care in any one year (Rosenwax, McNamara, Blackmore, & Holman, 2005). With increasing numbers of people identified as potential beneficiaries of palliative care, and not enough palliative care specialists, physicians become ever more important providers

of palliative care. Thus, physicians must play important roles in palliative care, especially since, as Gomes et al. reported in a recent systematic review, a majority of people would prefer to die at home (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013).

Primary care physicians are furthermore well-positioned to provide continued palliative care in conjunction with palliative care specialists, because they share the "same nature of [care]," as both "Can take the perspective of treating the whole person, their immediate, the application of best practice, and consideration of these issues beyond the physical to encompass psychosocial, practical, and spiritual ones. (Rubin et al., 2015)

There is evidence that physician involvement in the care of patients with cancer patients could improve quality of life, and the quality of death and dying (Klabunde et al., 2009; Mathieson et al., 1996).

In addition to being well-positioned to provide care, often patients who may benefit from palliative care are not referred to palliative care services. Sometimes this is because the treating physician is able to sufficiently address the palliative and supportive care needs, while in other cases, the physician may not consider the patient to be able to gain a benefit, may be reluctant to refer the patient because of stigma surrounding palliative medicine, or may consider to be late to refer the patient (Beernaert et al., 2015; N. Fadul et al., 2009; Rhondali et al., 2013). In the latter two cases, then, a physician with training in palliative care would be the ideal provider of palliative care.

The longitudinal nature of many patient-physician relationships with physicians may further strengthen physicians' abilities to provide palliative care. Patients in particular value personal relationships with their providers of palliative care, and the existence of an established relationship with their physician would facilitate good palliative care (Masel et al., 2016).

Moreover, there is an increasing volume of patients identified as being able to benefit from palliative care. This is because of the increasing acknowledgement of early palliative care as the desired model for care. In addition, proposed shifts from physician-driven referrals to a system of automatic

referral (where a patient is automatically referred based on performance status or other criteria), and systems of automatic screening for palliative care upon hospital admission,

may greatly increase the need for palliative care providers (Hui&Bruera, 2016). Add to this, the increase in uptake of palliative care in non-malignant diseases, and the population of potential patients who would benefit from palliative care will only increase in the future. Thus physicians must become front-line, primary palliative care providers.

It is interesting to note that many rural physicians may already “perform palliative care as a matter of course,” while their urban counterparts may not need to provide these services because of access to specialist palliative services (G. K. Mitchell et al., 2012).

Although palliative care provided by the physician may be valuable for patients with cancer and other life-limiting diseases, education of physicians in components of palliative care does not appear to be uniform and is limited where present.

In post-graduate training for medicine residents, the standards for a medicine residency program to gain accreditation include a requirement for residents to have some knowledge of palliative medicine. Thus, the experiences of residents across the country at different institutions, or in fact, even within the same institution, may vary greatly. For instance, a 2017 study at the University of British Columbia found that only 54% of their medicine residents had received five or more hours of palliative care education, and only 50% of residents completed a core palliative care rotation (Spicer et al., 2017). The types of training, furthermore, may vary

between each trainee; of all residents across disciplines at the University of British Columbia, who received any form of palliative care education, 77% received education about palliative care through lectures, 25% through rotations, and 21% through seminars (Spicer et al., 2017).

#### Continuity of Care

Continuity of care in primary care is “the relationship between a single practitioner and a patient that extends beyond specific episodes of illness or disease,” and includes “care of an

individual patient,” and “care over time,” (Haggerty et al., 2003). The patient’s perspective of the care is also important, and continuity of care is ultimately “the degree to which a series of discrete healthcare events are experienced as coherent and connected and consistent with the patient’s medical needs and personal context” (Haggerty et al., 2003). In particular, Haggerty et al.’s widely cited definition includes of three types of continuity: relational continuity, informational continuity, and management continuity.

Continuity of care is important especially for those with life-limiting illnesses (Heyland et al., 2006); these patients seek “the attention and friendship of one doctor whom they can come to trust and with whom they can share their hopes and fears” (Weatherall, 1994). Continuity of care is also associated with a higher level of trust patients have for their physicians, which could also improve quality of care overall (Mainous, Baker, Love, Gray, & Gill, 2001)

Physicians also often have long-term relationships with their patients, which can benefit patients receiving palliative care, particularly as patients transition to end-of-life care. The roles of physicians and palliative care specialists thus necessarily overlap at the end of life, and a prior history between a physician and a patient may help healthcare providers provide better care to the patient and his or her. In addition, physicians may be able to help coordinate care for patients in palliative care. For patients with life-limiting illness and potentially other co-morbidities, they may encounter a large number of physicians; one study following 50 patients in their cancer care reports patients met with a range of 13-97 physicians (median number 32) (Smith, Nicol, Devereaux, &

Cornbleet, 1999). One patient met with 31 doctors in six months, and another met with 73 physicians in two years. Having one central manager of care may help patients navigate the complex medical system, the myriad of healthcare providers, and the abundance of information, throughout their illness. Perhaps because of this, increased physician continuity of care is associated with decreased odds of visits to an emergency department in the last two weeks of life as well as hospital death (Almaawi, Pond, Sussman, Brazil, & Seow,



2014; Burge, Lawson, & Johnston, 2003; Burge, Lawson, Johnston, & Cummings, 2003). Thus, physician involvement in palliative care, particularly at the end of life, may help maximize information and organizational continuity for patients and their informal caregivers (Seamark et al., 2014).

#### Which Services?

physicians can perform a range of services for patients with life-limiting illnesses, including palliative and supportive care services. For instance, physicians may be well positioned to provide symptom management, psychosocial care, and prescriptions (Jaakkimainen, Upshur, Klein-Geltink, Maaten, & Schultz, SE, 2006).

While palliative care specialists provide pain and symptom management, care coordination, patient education, and caregiver support, general practitioners may be able to contribute these services as well, perhaps while consulting with or referring patients to palliative care specialists where more help is needed (Davies & Higginson, 2004; Michiels et al., 2007).

In addition, patients may face increasing psychosocial needs as their disease progresses, particularly those with advanced cancer; these needs are often unmet (Aabom & Pfeiffer, 2009). It has been suggested that a practitioner may be the best positioned to provide psychosocial care for many patients with advanced cancer, particularly as their disease progresses and their psychosocial needs (particularly emotional distress levels) increase; this is especially true for patients without access to specialized supportive care specialists (Aabom & Pfeiffer, 2009).

Care at home may also decrease incidents of hospitalization and emergency room visits for patients (Seow, Barbera, Howell, & Dy, 2010). Thus home care could potentially improve the quality of life at the end of life, and the quality of death.

#### Death at Home

Death at home is ideal for many patients with advanced cancer, as well as patients with advanced illness more generally; often, home is where loved ones are present and a resemblance of “normal” life can be achieved in a familiar environment (Davies & Higginson, 2004; Gomes & Higginson,

2006; H. Mitchell et al., 2015; Seamark et al., 2014). Dying at home is not only good for patients who desire it, but can also save on healthcare costs overall. Dying outside the home is costly to society; since 1976, approximately 30% of the Medicare budget in the United States has been used for care in the last year of life, many costs which are incurred through hospitalizations (Rao et al., 2002).

In one UK study, over half of interviewed patients with advanced cancer wish to die at home (58%), and 70% of patients would prefer to die at home if circumstances were ideal (Gomes & Higginson, 2006; Townsend et al., 1990). Furthermore, over half (63%) of informal caregivers also prefer their patients to die at home (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005). However, many who would prefer to die at home cannot or do not; only one-fifth of deaths occur at home in the UK (Seamark et al., 2014). It may be important to note that although dying at home may be considered ideal for many patients, the realities of home care at the end of life may be difficult for both the patients and their families. For instance, dying at home may need to involve the installation of medical equipment, changes to the structure and flow of the home, and many visits by healthcare professionals and support staff (Seamark et al., 2014).

Historically, women were responsible for care in the home and death in the home was more feasible. Though women remain primary unpaid caregivers in the majority of cases in contemporary. As a result, women are more likely part of the workforce than ever before, and less likely to be available as informal caregivers (Davies & Higginson, 2004). Furthermore, increasing globalization and more opportunities for migration make it less likely that members (who are often default caretakers) will live close to each other (Davies & Higginson, 2004). This shift in informal care affects the ability of people to die at home. However, for patients wishing to die at home, having home palliative care increases the chances of dying at home by more than 50% (Gomes, Curiale, Mccrone, & Higginson, 2013).

Thus, for the many patients with advanced cancer who express wishes to spend time at home as they approach the end of their life, this may be facilitated by including physicians into end of life care; this may also save on healthcare costs for

society as a whole. Continuity of care from the hospital to primary care is important in helping patients die at home. This continuity can be achieved by care from physicians, as well as by nursing staff, allied healthcare workers, and formal caregivers (Seamark et al., 2014).

## 2.6 Patient Perspectives on the Provision of Palliative Care by the Physician

There is a limited literature of patient perspectives on the role of their physicians in the provision of palliative care. As such, much of the published literature comprises of small, exploratory single-site studies conducted in urban centers. The limited number of studies published about cancer patients' perspectives on roles of physicians in their palliative care, means that there are many gaps in our knowledge. These gaps may be exacerbated by the methodological and design limitations in the studies reviewed here. The following section describes the perspectives of patients, on receiving palliative care from their physician.

### Continuity of Care

Continuity of care was an important theme in this body of literature. Specifically, patients expect relational continuity from their physicians.

In a study of Belgian patients in an urban centre, patients expected the physician to learn and remember "non-biomedical knowledge" about them, including their preferences, feelings, and personality. They expected their physician to give them "the right information [such as diagnoses] at the right time in a sensitive manner" (Michiels et al., 2007). Patients also perceived their respective physicians as playing a pivotal role in informational continuity; they "expected their physicians to manage the knowledge exchange," with specialists as well as other resources such as home care, though subjects had mixed attitudes about whether it should be the specialist or physician to initiate this exchange (Michiels et al. 2007).

Patients in Winnipeg, Manitoba also expected that it should be their physician who managed and coordinated their care, though the actual relationships varied among patients (Norman, Sisler, Hack, & Harlos, 2001). These study participants identified the care pattern with their physician as either sequential care (receiving care exclusively from an oncologist after diagnosis, exclusively from a palliative care specialist or

their physician after treatment), parallel care (receiving non-cancer related and supportive care from their physician concurrently with cancer treatment and palliative care), or shared care (receiving general and cancer-related care from their physician throughout and after treatment, with the physician playing a greater management role).

## 2.7 Barriers to Receiving Palliative Care from the Physician

Patient-identified barriers to continual care, and more generally to physician involvement in patients' palliative care, are many.

### *Lack of time*

A perceived lack of time, both on the part of the physician and the patient, was most universally cited in the literature as a barrier to receiving palliative care from the physician. For instance, subjects in a Belgian study stated that their physicians did not have enough time for them, particularly with physicians' holiday schedules and general unavailability after hours (Michiels et al., 2007). Patients also felt that after spending time in treatment in hospitals with specialists, it was too difficult to spend more time waiting in their physicians' waiting room as well. Furthermore, the subjects of 2009 Danish study felt that they did not want to "disturb" or "inconvenience" their physician for what they perceived as "small matters" (Aabom & Pfeiffer, 2009).

### *Loss of Contact*

It is common for patients to lose contact with their primary care physicians after their cancer diagnosis. Since physicians and their patients can lose contact with each other after the patient's cancer diagnosis, patients may find it difficult to transition back to the care of their doctor when they need palliative care (Aabom & Pfeiffer, 2009; McWhinney, Hoddinott, Bass, Gay, & Shearer, 1990; Norman et al., 2001). For instance, patients with advanced cancer interviewed by Norman et al. reported losing contact with their physician because of several reasons, including either the physician or patient moving, and distrust in the physician as a result of a delayed cancer diagnosis (2001). Loss of contact thus resulted in not receiving care from the physician during their illness.

### *Separation between the Physician and the Hospital*

Another common barrier cited in the literature, preventing physician involvement in care of patients with advanced cancer, was a perceived or real separation between the physician's practice and the hospital-based specialists and treatments. This was accompanied by a lack of communication between their health care providers, including allied health professionals, which became a main barrier for patients to be cared for by their physicians. Patients felt that there was a lack of communication between their specialists and physicians (E. A. Barnes et al., 2007; Norman et al., 2001). This lack of communication can be exacerbated when considering that physicians are often not involved in inpatient units at hospitals, particularly in urban centres (Norman et al., 2001). Further, Norman et al. found that a lack of strong connection with the physician (for instance, if the patient was healthy before the diagnosis) could prevent further connection with the physician after diagnosis.

### *Lack of Expertise on the Part of the Physician*

Many patients across the literature felt that they did not need their physician in their palliative care, or that the physician was not experienced enough to handle their palliative care. In addition, a weak or damaged relationship between patients and their physicians could stem from patient "distrust over delays in diagnosis" of their disease in the early stages (Norman et al., 2001). Subjects across the literature also felt that their physician lacked the knowledge to care for them (Michiels et al., 2007), had experiences of their physician being inexperienced with their treatment (Aabom & Pfeiffer, 2009), or simply felt that their primary care physician would be unable to help them (E. A. Barnes et al., 2007).

Researchers found that their patients felt their needs were met better by specialists, and that "no clear role" existed for their general practitioners (Norman et al., 2001), especially if their physician "lack[ed] initiative" (Michiels et al., 2007). Furthermore, a survey of cancer patients found that only 42% of 913 participants "rated their doctor as a very helpful source of information on symptom management" (Ashbury et al., 1998).

### *Strong Relationships with Hospital Staff*

Even if they did not have weak or damaged relationships with their physicians, patients cited strong relationships with hospital staff, in particular the nurses, as being a reason they did not consult their physicians. In these cases, hospital staff not only found solutions to their non-cancer related medical issues, but also gave them hope (Aabom & Pfeiffer, 2009). Patients also believed that their oncologists were responsible for their cancer care, and took care of all their medical needs (E. A. Barnes et al., 2007).

### *Costs*

Another barrier to physician involvement in patients' palliative care included financial restrictions of patients, who felt that they could not pay for physician visits in addition to their other medical costs (Michiels et al., 2007). For patients, although physician visits are covered by provincially funded, public healthcare, other costs associated with more physician visits (including transportation or hiring caregivers) could be restrictive for patients.

### *Facilitators to Receiving Palliative Care from the Physician*

Overall, general practitioners were valued by patients when they were accessible for appointments or telephone consultations, when they provided emotional and support, and for their role in managing their care through triage, referrals, and general physical care (Norman et al., 2001). Moreover, physicians were more likely to be perceived as part of a patient's care if patients had seen physician after their diagnosis, if the physician had been seen recently, if they were generally satisfied with their physician, and if the physician offered an on-call service (E. A. Barnes et al., 2007).

## **3 Conclusions**

Palliative care is an important area of care, including for patients with cancer. Early palliative care has been shown to be effective, and is increasingly considered the ideal model of palliative care delivery. However, this growing recognition of the effectiveness of early palliative care will also increase the demand for palliative care services. Since specialists require high levels of expertise and resources, physicians as a whole are the ideal providers of primary, front-line palliative care, in

addition to those physicians and other specialists who provide palliative care almost exclusively.

The perspectives of physicians regarding their provision of palliative care are well documented in the literature. The opinions of primary care physicians are critical in increasing their involvement in palliative care for patients with advanced cancer. They show that many physicians are already providing, or are willing to provide, at least some palliative care services. However, physicians cite many barriers to their provision of palliative care, including lack of time, lack of patient resources, lack of integration in healthcare, and lack of clarity of the role they can play in palliative care.

Patient perspectives are less well-documented. Existing literature suggests that barriers patients face when considering physician involvement in their palliative care include a lack of time, loss of contact with the physician, separation between their hospital-based care and the physician, strong relationships with hospital staff, lack of physician expertise in palliative care, and costs of care.

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