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Palliative Care
for Adults Living with Cancer

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Table of Contents

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Introduction

In 2020, more than 1.8 million people in the United States are expected to be diagnosed with cancer, including nearly 62,000 Michigan residents (Siegel et al. 2020). Despite being the second leading cause of death in the United States, medical advancements have led to a 29 percent decline in cancer deaths over the past 30 years (Siegel et al. 2020). Approximately two-thirds of cancer patients are living five years after their diagnosis, an increase from less than 50 percent in 1975 (Centers for Disease Control and Prevention 2019; National Cancer Institute 2020). In Michigan, there are more than 570,000 people living with a history of cancer (American Cancer Society [ACS] 2019).

With more people with a cancer diagnosis living for longer periods of time, more people are also living with symptoms from their cancer or side effects from their treatment (ACS 2019). Though the presence and severity of side effects vary based on the person, cancer type, and treatment method, they commonly include fatigue, pain, or emotional distress, among many others (ACS 2019; Henry et al. 2008). Side effects may occur during active treatment or in the months or years following treatment and can contribute to decreased quality of life by limiting daily functioning, impacting work productivity or employment status, or leading to psychological distress (ACS 2019; Henry et al. 2008).

The symptoms and side effects of cancer and its treatment may be alleviated in part through the use of palliative care. Palliative care is an approach to care that seeks to ease symptoms and improve overall quality of life for people with serious illnesses (such as cancer) and their families by addressing physical, psychological, emotional, and spiritual needs (ACS 2019; World Health Organization [WHO] n.d.). Due to its proven benefits and ability to be provided alongside curative treatment at any stage of a diagnosis, an increasing number of hospitals in the United States have established palliative care programs over the past 20 years (Center to Advance Palliative Care [CAPC] February 11, 2019; ACS 2019).

However, it is estimated that between 1 million and 1.8 million patients admitted to hospitals that could benefit from palliative care may not be receiving it (Morrison et al. 2015). Further, many patients are referred to palliative care specialists near the end of life, despite the potential for enhanced benefits when it is provided early in the disease course (Zhi and Smith 2015; Hui et al. 2018; Smith et al. March 2012).

Due to continued medical advances, an aging population, and other factors, the number of people living with serious illnesses is expected to continue to increase, with more than 22 million people anticipated to be living with a history of cancer in 2030 (ACS 2019; de Moor et al. 2013). As these trends continue, ensuring access to and delivery of palliative care is increasingly important. Palliative care providers at the MD Anderson Cancer Center have said, “The question is no longer whether palliative care should be offered, but what is the optimal model of delivery, when is the ideal time to refer, who is in greatest need of referral, and how much palliative care should oncologists themselves be providing?” (Hui et al. 2018). While palliative care can be offered to patients of any age, this paper describes palliative care and its uses for adult cancer patients. It distinguishes palliative care from hospice, highlights the benefits and barriers to delivering and receiving this care, and considers how palliative care can be incorporated into practice. It is particularly focused on the benefits of and barriers to specialty palliative care to encourage early referral to these providers.

Definitions and Types of Palliative Care

Palliative care has been studied and defined by a variety of entities. The World Health Organization (WHO) offers the following widely accepted definition:

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

Palliative care is designed to support any patient with a serious illness from the time of diagnosis throughout the disease course; it may involve symptom management, navigation of treatment options, advance care planning, or referrals to community resources; and can be used in conjunction with other life-prolonging therapies, such as chemotherapy or radiation therapy (National Hospice and Palliative Care Organization [NHPCO] 2019; WHO n.d.; Kelley and Morrison 2015). Palliative care is most frequently delivered in inpatient settings but can also be provided in outpatient or home-based settings and is provided by a team of healthcare providers, such as specialty trained physicians, advance practice providers, nurses, chaplains, and/or social workers to address the needs of patients and their families (WHO n.d.; Kelley and Morrison 2015). Most patients receive palliative care on an intermittent basis and increase use as their disease progresses (NHPCO 2019).

There are two main categories of palliative care—primary and specialty. Both forms are important components of cancer care focused on symptom management and quality of life for patients and their families but are delivered by different types of providers and offer varying levels of services to patients (Burt and Kamal 2018; Quill and Abernethy 2013). It is also important to distinguish palliative care from hospice care, which is only provided at the end of life.

Primary Palliative Care

Primary palliative care is commonly delivered by providers whose primary specialty is not palliative care, such as oncologists or primary care physicians (Bickel et al. 2016; Quill and Abernethy 2013). Primary palliative care typically includes some aspects of palliative care, such as basic symptom management and care coordination, delivered by these providers and their teams (Burt and Kamal 2018). While some oncologists also consider end-of-life care and advance care planning to be part of their service offerings, addressing all aspects of palliative care, including psychosocial or spiritual needs, is normally beyond their scope of practice (Bickel et al. 2016). Providers, including those that deliver primary palliative care, can be supported in their clinical work by referring patients to specialty palliative care for palliative care needs that are more comprehensive and beyond their capacity to provide.

Specialty Palliative Care

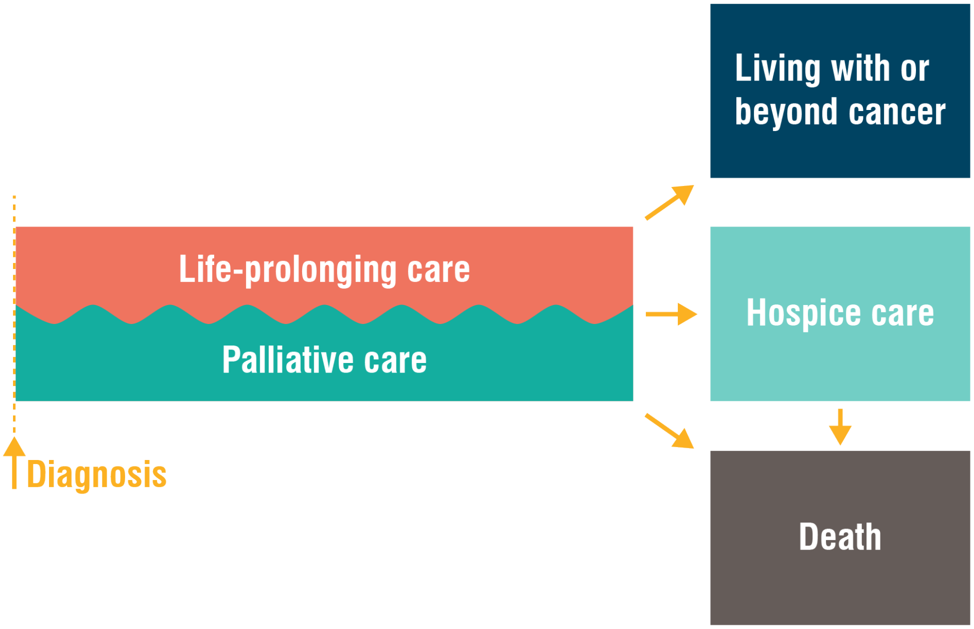
Specialty palliative care typically involves more complex and higher-need cases and is provided by a coordinated interdisciplinary team of board-certified providers that often includes physicians, advance practice nurses or physician assistants, social workers, and chaplains, and may also include pharmacists, dietitians, and other specialists (Kelley and Morrison 2015; Burt and Kamal 2018). Due to their specialty training in palliation beyond standard clinical or professional training, this team delivers a person-centered and holistic approach to care, which may include providing advanced symptom management, addressing complex psychosocial and spiritual needs, reexamining advance care planning, and assisting with communication and decision making among families, staff, and treatment teams (Burt and Kamal 2018; Quill and Abernethy 2013).

Distinguishing Palliative Care from Hospice

Palliative care is frequently associated and conflated with hospice, which is a specific kind of palliative care for patients at the end of life (Kelley and Morrison 2015; Centers for Medicare and Medicaid Services [CMS] 2019; National Coalition for Hospice and Palliative Care [NCHPC] 2018). Both types of interventions are delivered by interdisciplinary teams focused on improved symptom management and quality of life for people with serious illnesses and their families. However, while palliative care is a broad approach to care, hospice is a specific insurance benefit with differences in patient eligibility, receipt of curative treatment, service setting, and payment method.

The main distinguishing feature is that palliative care can be provided throughout the entire disease course alongside curative treatment, from the time of diagnosis onwards, while hospice is only provided once life-prolonging care has stopped, as shown in Exhibit 1 (CAPC July 2020). Hospice eligibility is largely based upon payer reimbursement criteria and includes a provider assessment and certification to identify patients that qualify (Kelley and Morrison 2015). Patients with Medicare—the most common hospice payer—are eligible if they have less than six months to live and agree to forgo curative treatments, such as chemotherapy and radiation (Kelley and Morrison 2015).[1]

EXHIBIT 1. Continuum of Care for Palliative Care



Source: Adapted from the Center to Advance Palliative Care.

Hospice can be delivered wherever the patient resides, which is frequently a patient's home or nursing home, but can also be provided in other settings, such as an inpatient facility (Kelley and Morrison

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[1] Under Medicaid, some states outside of Michigan allow patients that have up to one year to live to receive hospice care (CMS 2015).

2015). Hospice is paid on a per-diem basis by Medicare to cover services a patient needs related to their hospice-certifying diagnosis (CMS 2019). Many other insurers, such as Medicaid and private payers, follow these Medicare policies, though it may vary by payer (Kelley and Morrison 2015; Michigan Department of Health and Human Services 2020). In contrast, palliative care—which can be covered by private insurance, Medicare, or Medicaid—is typically reimbursed based on each service delivered, though bundled services and other alternative payment models between payers and providers are being explored (CAPC n.d.; NCI 2017). A comparison of the differences is shown in Exhibit 2.

EXHIBIT 2. Differences Between Palliative Care and Hospice

	Palliative Care	Hospice
Patient Eligibility	- Patients can be at any stage in a serious illness.	- Patients must be terminally ill with a life expectancy of less than six months.
Curative Treatment	- Can be provided together with other medical treatments.	- Patients must forgo disease-modifying treatments, such as chemotherapy.
Service Setting	- Can be delivered in inpatient, outpatient, or home-based settings.	- Typically delivered in a home or nursing home, or occasionally an inpatient setting.
Payment Method	- Can be reimbursed by commercial insurers, Medicaid, and Medicare and is typically fee for service.	- Medicare, and other insurers, pays hospice providers a per-diem rate to cover daily costs of care.

Benefits of Specialty Palliative Care

According to the American Society of Clinical Oncology (ASCO), palliative care is an essential part of comprehensive cancer care (Ferris et al. 2009; Ferrell et al. 2017). Specialty palliative care addresses many aspects of quality cancer care, as defined by ASCO's quality measures, including assessing and managing pain continuously, communicating with patients about the intent of curative treatments, assessing emotional well-being, documenting advance directives, providing less intensive treatments near the end of life, and limiting the number of deaths occurring within the intensive care unit (ASCO June 2020). Studies have shown that palliative care has many benefits, including improved quality of life for patients, improved satisfaction for caregivers and families, and decreased healthcare costs.

Benefits to Patients

Palliative care has been shown to provide many benefits to patients, including improved quality of life, improved patient-provider communication, increased care coordination, and increased survivability.

Improved Quality of Life

Specialty palliative care is associated with improved quality of life among people with different types of cancer, particularly when provided early in the disease course (Gaertner et al. 2017). Quality of life may include clinical aspects, such as addressing a patient's physical symptoms (e.g., pain or nausea) or emotional health (e.g., anxiety or stress). Studies have demonstrated the potential for palliative care to reduce complex physical symptoms, such as fatigue, pain, and difficulty breathing, with one study even showing a 66 percent reduction in overall symptom burden (Kavalieratos et al. 2016; Ferrell et al. 2015; Yennurajalingam et al. 2011). Other studies have indicated that advanced cancer patients who received specialty palliative care along with anticancer treatment have lower psychological distress, such as depression, compared to patients who only received oncology care (Bakitas et al. 2009; Ferrell et al. 2015; Greer et al. 2018; Yennurajalingam et al. 2011). Due to its ability to provide symptom relief, among other benefits, ASCO recommends all cancer patients with an advanced disease and/or high symptom burden receive palliative care in addition to regular oncology care (Ferrell et al. 2015).

Specialty palliative care is holistic and may include nonclinical interventions, such as communicating with patients to align care goals or using music, aromatherapy, or relaxation techniques to provide comfort to patients (Coelho et al. 2016). Spirituality—the beliefs, values, traditions, or practices through which individuals seek meaning and purpose—is often a concern among people with serious illnesses but is one aspect of quality of life that is not frequently addressed in clinical settings (NCHPC 2018; Rangachari and Smith 2013; Kelley and Morrison 2015). However, many palliative care guidelines emphasize the importance of addressing spirituality as a fundamental aspect of patient and family centered care, which has been shown to improve patient satisfaction and decrease emotional distress (NCHPC 2018; Rangachari and Smith 2013; Kelley and Morrison 2015).

Improved Patient-Provider Communication

Studies have shown that people with advanced cancer often have an inaccurate perception of treatment effects and outcomes, which could lead them to choose therapies that have high risks and/or limited benefits and may reduce quality of life or increase financial costs (Rangachari and Smith 2013; Ghandourh 2016). Early palliative care has been shown to improve patient knowledge of their prognosis and make them less likely to choose treatments that are less effective (Temel et al. 2010; Zhi and Smith 2015).

In addition, while oncologists and palliative care specialists are both likely to discuss symptom management, prognosis, and treatment options, palliative care specialists are more likely to communicate with patients about coping with their illness and advance care planning, as well as offering support to their caregivers and family (Hagan Thomas et al. 2019; Zhi and Smith 2015). Further, specialty palliative care providers are trained to continually communicate about the goals of care—which may include discussion of advance directives and facilitated communication among patients, families, and clinical staff—throughout cancer treatment, including during times of prognosis change, rather than only once at the outset of care (Zhi and Smith 2015; Rangachari and Smith 2013).

Increased Care Coordination

Patients with cancer often receive care from many different providers with different care specialties, which can lead to a lack of coordination, and is associated with poor symptom control, medical errors, and higher costs (Sheinfeld Gorin et al. 2017; Weaver and Jacobsen 2018). Many palliative care guidelines, such as the latest from the NCHPC, emphasize the importance of interdisciplinary care and care coordination for palliative care patients, particularly during care transitions (NCHPC 2018; Greer et al. 2013; Bakitas et al. 2009; WHO n.d.). This focus on coordination and continuity of care in specialty palliative care helps to ensure patient goals are considered across providers and healthcare settings and may help to prevent unnecessary resource use (NCHPC 2018; Greer et al. 2013).

Increased Survivability

Palliative care may increase survival for some people with certain types of cancer (Zhi and Smith 2015). One study found that newly diagnosed lung cancer patients who received specialty palliative care and standard oncology care had a median survival of 11.6 months, which was 2.7 months longer than those at the same hospital who received oncology care only (median survival of 8.9 months) (Temel et al.

2010). In fact, the patients who received early palliative care had longer survival despite receiving less aggressive care at the end of life (Temel et al. 2010). Another study found that palliative care integrated early in the disease course improved survival more than palliative care implemented later. Advanced cancer patients who received specialty palliative care immediately following their cancer diagnosis had a median survival of 6.5 months longer than those who began palliative care three months after their diagnosis (Bakitas et al. 2015). Palliative care may have additional positive benefits that could contribute to higher survival rates than patients who do not receive palliative care, such as helping patients choose to complete their course of chemotherapy or radiation (Cheville et al. 2015).

Benefits to Caregivers and Families

The benefits of palliative care extend beyond the patient to caregivers and families, whose quality of life and well-being are often impacted by a patient's cancer diagnosis but are not typically included in patient care (Fujinami et al. 2012; Kusano et al. 2012). Palliative care services include time devoted to intensive family meetings, patient and family counseling, bereavement follow-up, and communication between patients, families, and physicians. Through these types of services, palliative care has been shown to provide emotional support and improve family satisfaction with care, compared to families of patients not receiving palliative care (Casarett et al. 2010).

Early initiation of palliative care may produce enhanced benefits for caregivers and families. One study found that caregivers of advanced cancer patients who received specialty palliative care shortly after diagnosis had lower depression scores compared to caregivers of patients with delayed initiation (Dionne-Odom et al. 2015). Another found that caregivers of people with advanced cancer who were referred to early palliative care had increased satisfaction compared to caregivers of patients who received standard oncology care only (McDonald et al. 2017). An additional study showed that early palliative care was associated with greater family satisfaction with care, higher ratings of respectful care and communication, and emotional and spiritual support, compared to families of patients who received palliative care one week before death (Carpenter et al. 2017).

Benefits to Health Systems and Providers

Providers and health systems can also experience benefits of palliative care. Studies have shown that palliative care may decrease healthcare utilization and costs, improve performance on quality measures, and increase provider satisfaction and communication with patients.

Decreased Healthcare Utilization and Cost Savings

Nearly 80 percent of crisis emergency department visits and hospitalizations are due to exacerbated symptoms, such as worsening chronic pain in cancer patients (CAPC November 2019). Through improved symptom management, tailored treatments, and comprehensive discharge plans, specialty palliative care provided in inpatient units has been shown to reduce readmissions in advanced cancer patients by 48 percent (CAPC February 3, 2019; Adelson et al. 2017). Early outpatient specialty palliative care may reduce emergency department visits by 35 percent and hospital admissions by 50 percent among cancer patients (CAPC February 3, 2019).

These reductions in healthcare utilization along with improved connections with optimal care settings and reduced length of stay contribute to health system cost savings (Meier and Sieger 2018; American Cancer Society Cancer Action Network [ACS CAN] 2020a; May et al. 2017). Palliative care consultation is associated with an average cost reduction of more than $4,250 per cancer patient admission (Meier and

Sieger 2018). This amounts to savings of approximately $1.3 million per year for a 400-bed hospital delivering specialty palliative care to 500 patients per year (Morrison et al. 2008; Meier and Sieger 2018). Other studies have estimated health system cost savings from palliative care programs to be between $1,300 to $12,000 per patient, depending on factors such as the type of illness, care setting, survival, and timing of the intervention (ACS CAN 2020a; Brumley et al. 2003; Brumley et al. 2007; Khandelwal et al. 2016; May et al. 2015; May et al. 2018; Lustbader et al. 2017). According to the CAPC (2018), the typical return on investment for health systems is between two to three dollars saved for every dollar invested in specialty palliative care (Meier and Sieger 2018).

In addition to reducing health system costs, fewer high-cost emergency department visits or inpatient admissions as well as decreased length of stays may contribute to cost savings or improved quality of life for patients.

Improved Performance on Quality Measures

Specialty palliative care delivered to cancer patients in inpatient and community-based settings has been shown to improve hospital performance on quality measures—such as all-cause readmissions, total cost, and experience of care—among providers receiving reimbursement from Medicare, Medicaid, and commercial payers (CAPC July 2020; Adelson et al. 2017; Cassel et al. 2015; Ranganathan et al. 2013). High-quality performance on many of these quality measures can have positive financial implications for health systems through CMS payment programs and other shared-risk models (Meier and Sieger 2018; Cassel et al. 2016). Some CMS measures for its merit-based incentive program that align with palliative care services include having a low percentage of cancer patients receiving chemotherapy in the last 14 days of life and conducting advance care planning (ASCO February 2020). Palliative care has also been associated with reducing patient length of stay by up to 13 percent, which can also contribute to cost savings (May 2015; May 2017; Khandelwal et al. 2015; Starks et al. 2013).

Additional Provider Benefits

Though the impact of palliative care on providers has not been widely studied, there is some evidence of a positive impact on providers whose patients receive specialty palliative care. Quality provider communication, which is an emphasis of many palliative care programs, can enhance provider empathy, reduce burnout, and improve patient outcomes (CAPC November 2019; Kelley and Morrison 2015). One study found that adding a palliative care specialist to an oncology group practice improved patient, family, and provider satisfaction, while saving referring oncologists nearly three hours of time per referral to palliative care due to shared patient care (Muir et al. 2010).

Barriers to Delivering or Receiving Specialty Palliative Care

Despite its many benefits, there are challenges to delivering and receiving palliative care, including lack of standardization in making referrals to specialty palliative care, lack of patient and provider education, limited access, and payment issues.

Lack of Standardization

While ASCO, the National Comprehensive Cancer Network (NCCN), and other organizations recommend early referral to specialty palliative care, there is not a standard model for integrating specialty palliative care into clinical practice (Geerse et al. 2018; Hui et al. 2018). This lack of standardization may contribute to variation in primary palliative care provider practices as they relate to communicating with patients about specialty palliative care and referring patients to specialty palliative care at different frequencies or times.

Limited Communications Training for Primary Palliative Care Providers

Many oncologists and other clinical providers do not receive formal training in effective patient communication, which may limit their ability to comfortably introduce the concept of specialty palliative care with patients (CAPC November 2019; Baile et al. 2011; Kaufmann and Kamal 2017). One study found that approximately 70 percent of physicians reported having no formal training in communicating compassionately and effectively about advance care planning or goals of care, while 66 percent of intensive care unit nurses indicated having insufficient training to discuss prognosis, goals of care, or palliative care with patients (Fulmer et al. 2018; CAPC November 2019). Without such training, providers may be focused only on clinical aspects of care, reluctant to engage in sensitive topics, or communicate in ways that contribute to cancer patients having negative care experiences, misperceptions about their prognosis or treatment, or limited awareness of support options, such as palliative care (Ghandourh 2016; Rocque and Cleary 2013; CAPC November 2019). However, communications training—a focus of specialty palliative care providers—has been shown to improve patient perspectives of care experiences, improve provider empathy, and reduce burnout (CAPC November 2019).

Limited Guidelines for Patient Referral

There are few and inconsistent guidelines for referring patients to specialty palliative care, especially as an early intervention. While many palliative care guidelines recommend integrating palliative care into standard oncology care early in the disease course, it may be difficult for providers to identify the optimal point of referral, as supportive services have historically been offered only to terminally ill patients at the end of life (Geerse et al. 2018; Hui et al. 2018). While ideal timing may depend in part upon individual patients or healthcare systems, studies have shown increased benefits to patients when specialty palliative care referral was conducted within three months of an advanced cancer diagnosis (Hui et al. 2018).

Some oncology care providers have implemented routine screening or automatic consultation based on specified criteria—such as identification of advanced cancer—to identify and refer patients to specialty palliative care. Some studies have shown that this standardized approach increases identification of patients who would benefit from specialty palliative care, reduces hospitalizations, and enhances communication between providers and patients (Glare et al. 2011 and Adelson et al. 2017). However, the benefits of automatic referral may not outweigh negative effects, as routine screening may add time to already busy clinical workloads, may be difficult for some healthcare systems with limited resources to implement, and may remove the personalized approach to identifying patients with the greatest symptom intensity or other support needs (Hui et al. 2018). Further, there are not standards in place to guide design or implementation of automatic referral criteria (Kistler et al. 2020).

Lack of Patient and Provider Education and Understanding

A lack of patient education and understanding about palliative care can be a major barrier to receiving services, as many patients are either unaware of it or do not want to engage in it because of the misconception that palliative care is only provided at the end of life. Studies have shown that between 70 and 90 percent of adults in the United States have either limited or no knowledge of palliative care (Public Opinion Strategies [POS] 2011; Trivedi et al. 2019). Another found that even individuals who indicated awareness of palliative care reported negative associations and inaccurate knowledge—such as that palliative care requires stopping other treatments (Taber et al. 2019). Studies have shown that the term “palliative care” is mistakenly perceived as giving up on treatment or considered to be “distressing and reducing hope to patients and families,” with one-third of surveyed cancer patients believing it is only intended for end-of-life care or terminally ill people (Lo and Buss 2019; Fadul et al. 2009; Zhi and Smith 2015; ACS CAN 2020b; Collins et al. 2018). These misperceptions may lead to underutilization of services (Johnson Shen and Wellman 2019). However, once informed about palliative care, 92 percent of survey respondents said they would consider palliative care for themselves or their families (POS 2011).

In addition to misunderstandings potentially influencing patient behaviors, the term’s association with end-of-life care may also impact provider attitudes. This could limit early referral, as some providers may have misconceptions themselves or fear referral will alarm patients and families (Fadul et al. 2009; Kavalieratos et al. 2014; POS 2011; Smith et al. February 2012). Additionally, this may further reduce patient understanding of palliative care, as providers may not correct patients who conflate palliative care with end-of-life care or may pass inaccurate information on to patients themselves.

Describing palliative care as supportive care that can be provided simultaneously with, and as a supplement to, standard cancer treatment could help to reduce stigma. Some organizations, such as the American Cancer Society, have already begun using the term “supportive care” interchangeably with “palliative care” (Lo and Buss 2019). One study found that patients were more likely to associate the term “supportive care” with enhanced communication and psychological and social support, compared to “palliative care” (Lo and Buss 2019). Oncologists and providers have indicated that they would be more likely to refer patients earlier in the disease course for palliative care if it were referred to as supportive care (Fadul et al. 2009). After one institution changed the name of its inpatient and outpatient services from palliative care to supportive care, palliative care consults increased by 41 percent and patients were more likely to be seen earlier in their disease course (Dalal et al. 2011).

Limited Access

Access to palliative care services is limited due to a variety of factors, such as provider shortages, geography, patient characteristics, and lack of community-based and outpatient services.

Provider Shortages

Provider workforce shortages may be one of the largest issues facing palliative care in the coming years (Hughes and Smith 2014). While the majority of hospitals have established palliative care programs in the past decade, staffing levels of those programs vary greatly and may need to be further evaluated to determine the appropriate number and type of staff to meet patient needs (Dumanovosky et al. 2015). One study estimated that between 6,000 and 18,000 additional physicians are needed to meet the current demand for palliative care in inpatient settings in the United States (Kelley and Morrison 2015). Another found that there is only one hospice or palliative medicine physician for every 20,000 older adults with a life-limiting illness (Hughes and Smith 2014). Further, due to an aging population and increase in cancer prevalence and survival rates, these differences are expected to grow. Both the oncology and palliative care workforce are projected to face a 40 percent shortfall in the coming years (Hughes and Smith 2014). Expanding primary palliative care skills among providers and increasing use of an interdisciplinary team may help decrease workforce shortages to address patient needs (Kelley and Morrison 2015; Geerse et al. 2018; Hui et al. 2018).

Geography

Across the United States, 72 percent of urban hospitals have palliative care programs, compared to 34 percent of rural hospitals (National Palliative Care Registry [NPCR] 2015). In Michigan, 81 percent of hospitals in urban regions have palliative care programs, compared to roughly half (52 percent) of hospitals in rural areas (NPCR 2015). Rural areas typically have small hospitals with 50 or fewer beds, which are less likely to have the number of patient admissions to support a full palliative care program (Morrison et al. 2019). Further, rural health systems often have difficulty attracting providers, particularly highly trained specialty palliative care providers (Lynch 2012). Even when providers are present, patients may still have difficulty accessing services due to the need to travel long distances for them (Lynch 2012). Use of telehealth services may help to improve access in rural areas, though recent expansions during the coronavirus (COVID-19) pandemic that began in early 2020 are temporary and may not address all access issues for those who live in areas with limited Internet or cell phone service, are not covered by Medicare, or may have difficulties using the technology (CAPC June 2020; CMS 2020).

Patient Characteristics

Patient characteristics, such as ethnicity, physical ability, race, religion, and sexual orientation can also have an impact on access to palliative care. Studies have found that individuals who identify as a member of a racial and ethnic minority group are less likely to receive palliative care (Cole et al. 2019; Cain et al. 2018). One study evaluating referral of patients with four different types of cancer found that 22.5 percent of white, 20 percent of Black, 17.9 percent of Asian, and 15.9 percent of Hispanic patients were referred to specialty palliative care (Cole et al. 2019).

Other studies have suggested that patient characteristics may shape how they view palliative care, communicate about care, and determine preferences for advance care planning, life-sustaining treatments, pain management, and care settings (Lynch 2012; Cain et al. 2018). These differences are often not fully understood by providers, which may contribute to “people of color, of diverse sexual orientation, and disabled [being] less likely to receive care that aligns with their wishes,” which may include palliative care (Cain et al. 2018).

Lack of Community-Based and Outpatient Palliative Care

In the United States, only 66 percent of comprehensive cancer centers and 29 percent of regional cancer centers are equipped to deliver early palliative care in outpatient settings (Bruera and Yennurajalingam 2012). Over the past decade, however, demand for outpatient and community-based palliative care has increased, including among patients in nursing home settings (Kelley and Morrison 2015; Burt and Kamal 2018). Community-based palliative care can be important for patients of private practice oncologists and other providers who do not have access to a large healthcare system, so are unable to refer to specialty palliative care in inpatient settings. One model showed that palliative care delivered through a partnership between a private oncology practice and outpatient palliative care service reduced symptom burden by 21 percent and improved provider satisfaction (Muir et al. 2010; Rangachari and Smith 2013). Additional studies have shown that community-based or outpatient palliative care can enhance symptom management, improve patient and family satisfaction, and reduce use of hospital care (Kelley and Morrison 2015; Hui et al. 2014; Finlay et al. 2018). Though more research is needed to identify which services are most effective in different settings, providing care in an outpatient or community setting has the potential to increase patient access to palliative care (Geerse et al. 2018; Hui et al. 2010; Parish 2019).

Limited Reimbursement for Services

Another barrier to delivering or receiving palliative care is limited reimbursement for the services provided by members of the interdisciplinary palliative care team. While palliative care teams are made up of multiple staff, only some can bill for their services; thus, revenue from palliative care programs typically does not match program costs (Meier and Sieger 2018). Physicians and advanced practice providers can bill for inpatient and outpatient palliative care consultation services under Medicare and commercial insurance (Meier and Sieger 2018; Kelley and Morrison 2015). However, nonmedical personnel, such as social workers and chaplains, generally cannot receive reimbursement for the services they provide, and palliative care offered in alternative settings, such as homes or nursing homes, may not be reimbursed in some cases (Kelley and Morrison 2015). Limited reimbursement may make it difficult for private-practice oncologists and others outside of a health system to financially support delivery of specialty palliative care (Finlay, Rabow, and Buss 2018).

Telehealth has been increasingly explored as an alternative delivery option for palliative care. Medicare, Medicaid, and private health plans may cover telehealth for palliative care services to varying degrees, such as use of videoconferencing or telephone for transitional care management or advance care planning services (CAPC June 2020). During the COVID-19 pandemic that began in early 2020, CMS has temporarily allowed for increased use of telehealth under Medicare for additional providers and for services such as advance care planning and home visits, though the modifications are set to expire after the public health emergency ends (CAPC June 2020; CMS 2020). Federal and state laws around telehealth may continue to evolve and the long-term implications are unknown.

Surveys of cancer center executives have shown that they view limited reimbursement and constrained hospital budgets as the largest barriers to expanding access to palliative care in cancer centers (Hui et al. 2010; Davis, Strasser, and Cherny 2015). However, most agreed that palliative care should be integrated with oncology care (Hui et al. 2010). Many hospitals invest in palliative care programs because they believe they will save money through decreased use of other medical services, a possibility that some studies support (Meier and Sieger 2018).

Palliative Care in Practice

As providers work to incorporate primary palliative care into practice and refer to specialty palliative care providers, health systems should encourage expanded use by providing access to specialty palliative care teams; ensuring those teams are made up of core members, including a trained physician, advanced practice provider, social worker, and chaplain; training non-specialty palliative care providers on when and how to introduce specialty palliative care; and developing systems to coordinate referrals and maintain provider communications. The following sections include a program profile highlighting real-world examples of palliative care delivered in various settings in Michigan, as well as resources for primary palliative care providers to support their work.

Michigan Specialty Palliative Care Program Profile

The following composite profile includes information about specialty palliative care programs from Michigan cancer centers and health systems. All participants in this whitepaper project were invited to submit a profile, and there were eight responses in total (Appendix B). The profile serves as an example of Michigan palliative care programs but is not intended to represent all programs in Michigan, particularly those in rural areas that did not participate in the workgroup and may have more limited programs due to access and resource barriers.

Overall, the composite profile largely reaffirms the literature findings on the benefits of and barriers to specialty palliative care. There were no major differences between programs related to care setting, though there were variations across programs in some areas, such as specialty palliative care team members and oncology team collaboration. The profile also includes information on referral practices; barriers to delivery; and benefits to patients, caregivers and families, and providers.

Overview

Each of the programs provide specialty palliative care in inpatient and outpatient settings to support patients and their families in managing symptoms, setting care goals, and discussing difficult topics related to prognosis and treatment options. While one health system provides limited outpatient palliative care that offers advance care planning services only, other programs have expanded to provide palliative care in additional settings, including local skilled nursing facilities, long-term acute care hospitals, and patients' homes.

Specialty palliative care team members vary across programs. While every program employs at least one physician and most include at least one social worker, nurse practitioner, or chaplain, additional staff are unique to each palliative care program. Other specialty palliative care team members may include a nurse, program administrator, surgeon, dietitian, music therapist, or psychologist, among others.

Each specialty palliative care program indicated that their care teams and oncology teams work closely together, though the integration strategies differed. Several programs offer regular palliative care clinic sessions or participate in cancer-related committees. Others promote in-person interactions between collocated staff, provide after-hours consults, or include palliative care in oncology fellows' curricula.

Referrals

Patient symptoms, prognosis, and need for support are the primary drivers for patient referral to specialty palliative care programs. Other factors that may be considered include patient need for an advance care plan, high healthcare utilization, frequent readmissions, or level of distress. Some programs have considered implementing standardized referral practices, such as referring all stage four cancer patients or patients in need of specialty physical or psycho-social support.

Specialty palliative care programs promote early referral to their programs in a variety of ways, including promoting interdisciplinary collaboration; offering resources from the Center to Advance Palliative Care (CAPC) to staff; incorporating palliative care education into staff orientation, training, or resident programs; and conducting community outreach to primary care offices.

Barriers

Each of the specialty palliative care programs identified barriers to specialty palliative care delivery due to misconceptions about what palliative care is, with some patients confusing palliative care with hospice and others not understanding how it supplements oncology care. Some of the palliative care programs have addressed this by providing community and patient education. Other barriers include limited capacity of specialty palliative care teams, late referrals, patient mobility, and gaps in insurance. Programs addressed some of these barriers by hiring additional palliative care staff, providing interdisciplinary education, expanding use of telehealth, and improving care coordination.

Benefits

Program staff identified benefits to patients, families and caregivers, and providers from specialty palliative care. Major patient benefits include improved symptom management, increased psychological and spiritual support, improved understanding of prognosis and care options, tailored care plans, coordinated care, and enhanced communication with providers. One health system shared that patient symptoms often improve within 24 hours of receiving specialty palliative care. Another reported that patients have also experienced reduced length of stays due to improved symptom management, avoided unnecessary treatments at the end of life, and are referred to hospice sooner.

Families and caregivers receive many of the same benefits from specialty palliative care as patients, such as improved care satisfaction, increased psychological and spiritual support, and enhanced understanding of prognosis and treatment options, as well as bereavement support. One family expressed their gratitude for the specialty palliative care program after facing situations with both their mother and father one year apart, one of whom received palliative care services and one who did not. The family said that the extra support provided by the palliative care program made the treatment process easier.

Providers also benefit from a collaborative strategy where oncologists focus on complex treatment, while specialty palliative care teams target patient symptoms and care goals. One program indicated that when patients are engaged in specialty palliative care, providers receive decreased requests for treatments that have limited benefits. Some specialty palliative care programs also identified benefits to health systems, including through reduced emergency department visits and readmissions and increased cost savings from aligning patients’ goals with care. However, most programs shared that they do not have data related to these measures.

These existing specialty palliative care programs provided several considerations for other health systems interested in implementing a specialty palliative care program. Factors that may contribute to program success include:

- Identifying a targeted patient population.
- Requiring staff to receive palliative care education and/or certification.
- Involving support staff from other departments (e.g., billing or grants departments).
- Engaging leadership and health system commitment to returns on investment.
- Hiring a core team (physician, nurse/nurse practitioner, social worker, and chaplain).
- Using outside resources, such as those from CAPC.

Provider Resources

There are many resources available for providers to incorporate palliative care into their practice. The following sections provide a sample of resources available for becoming familiar with quality standards and guidelines, developing an interdisciplinary team, communicating about palliative care, making appropriate referrals, obtaining reimbursement, and utilizing data to assess programs.

Using Quality Standards and Guidelines

American Society of Clinical Oncology (ASCO) offers its own set of guidelines for implementing palliative care into standard oncology practice. These guidelines were developed by an expert panel that conducted a systematic review of randomized clinical trials. They offer evidence-based recommendations addressing six overarching clinical questions—such as the most effective way to care for patients, most practical models of palliative care, and type of patients to be referred to palliative care services—to patients diagnosed with cancer and their families, providers, and palliative care specialists. Overall, the guidelines recommend that patients with advanced cancer should receive interdisciplinary specialty palliative care services early in the disease course, concurrent with active treatment, in inpatient or outpatient settings. ASCO's guidelines are available at https://www.asco.org/research-guidelines/quality-guidelines/guidelines/patient-and-survivor-care#/9671.

Center to Advance Palliative Care (CAPC) provides a variety of tools, trainings, and other materials on palliative care for providers on its website. CAPC created a toolkit on best practices for delivering quality care to patients with serious illnesses. It includes National Consensus Project for Quality Palliative Care Clinical Practice Guidelines (NCP Guidelines), other clinical guidelines, professional certifications in palliative care, program certifications in palliative care, quality standards and incentive programs, and measurement and benchmarking. CAPC's toolkit is available at https://www.capc.org/defining-and-measuring-quality/.

The National Comprehensive Cancer Network (NCCN) has its own version of palliative care guidelines. The guidelines are drafted by cancer experts throughout the United States and reflect their views of the currently accepted approaches to treatment. The most recent version was updated in 2020 and includes definitions and standards of palliative care, assessment and interventions by the oncology team, criteria for consultations with a palliative care specialist, the benefits and burdens of anticancer therapy, and information about social supports, preparing patients and families for end-of-life care, and advance care planning. Guidelines require a login but are available at https://www.nccn.org/professionals/physician_gls/default.aspx. The 2018 version is available at https://oncolife.com.ua/doc/nccn/Palliative_Care.pdf.

The National Hospice and Palliative Care Organization (NHPCO) contributed to the 2018 NCP Guidelines, which are intended for palliative care specialists and other clinicians who care for people with serious illnesses. The guidelines include recommendations for implementing eight components of palliative care, including approaches to addressing an individual's physical, psychological, and spiritual needs, and offer tools and resources specific to each of those components. The NCP Guidelines are available at http://www.nationalcoalitionhpc.org/ncp/.

Developing an Interdisciplinary Team

CAPC and the NHPCO provide links to specialty palliative care certification resources for a variety of disciplines, including physicians, nurses, social workers, and chaplains. Both organizations also offer resources for program certification in palliative care for hospital and community-based providers from accrediting organizations, such as the Joint Commission Palliative Care Certification, Community Health Accreditation Partner Palliative Care Certification, and Accreditation Commission for Health Care Palliative Care Distinction. CAPC further provides information on building and supporting a palliative care team, such as day-to-day operations, team roles, and working with referrers. For more information, visit CAPC's quality and standards page (link provided in Using Quality Standards and Guidelines subsection) or their interdisciplinary team page at https://www.capc.org/toolkits/building-and-supporting-effective-palliative-care-teams/, or visit the NHPCO at https://www.nhpco.org/palliative-care-overview/palliative-care-accreditation/.

Communicating About Palliative Care to Patients

ASCO offers guidelines on best practices for cancer providers when communicating with patients and their families. The guidelines recommend providers attend communication skills training, clearly establish goals of care, initiate conversations of end-of-life preferences, and make patients aware of all treatment options. Guidelines are available at https://ascopubs.org/doi/pdf/10.1200/JCO.2017.75.2311.

The Communication Skills Pathfinder offers communications training for providers and links to a variety of studies analyzing provider communications, including several reviewing best practices in communicating about serious illness care goals and transitions of care. The resource list can be found at https://communication-skills-pathfinder.org/resources-insights/.

VitalTalk is a resource for providers to enhance communications skills for serious illnesses. It provides evidence-based trainings to empower clinicians and institutions. More information is available at https://www.vitaltalk.org/.

Making Appropriate Referrals

The ASCO guidelines consider which patients should be referred and when, including triggers that should be used to prompt specialty palliative care referrals. The recommendations include early referral and cautions against criteria triggering automatic referral due to the resources needed and potential to miss patients with early-stage cancer in need of referral.

Referral criteria can be found on CAPC's website, which includes a list of triggers for referral to a specialty palliative care team, at https://www.capc.org/documents/286/.

The NCCN guidelines include a section on assessment by an oncology care team and criteria for referral to a palliative care specialist. Some criteria include limited anticancer treatment options, need to clarify goals of care, high risk of pain resistant to conventional interventions, high distress scores, or communication barriers.

Obtaining Reimbursement

CAPC offers a comprehensive toolkit with information on financing a palliative care program, including estimating costs and prices, understanding value-based payment models, measuring outcomes to show value, and maximizing provider reimbursement through use of advance care planning codes, chronic care management, and complex chronic care management. More information can be found at https://www.capc.org/toolkits/funding-a-palliative-care-program/.

NHPCO provides information about reimbursement from CMS, including enrolling in Medicare Part B for providers, billing for palliative care services through transitional care management, and understanding quality payment programs. NHPCO's CMS page provides more information as well as information about the quality payment program at https://www.nhpco.org/palliative-care-overview/macra-quality-payment-program/.

Assessing Programs

Some data is available for primary and specialty palliative care providers to use to compare programs, measure quality, and demonstrate the value of palliative care. The Palliative Care Quality Collaborative is a new organization launching in 2020 to create a unified palliative care registry. It combines aspects of different palliative care registries that previously existed, including the National Palliative Care Registry, Palliative Care Quality Network, and Global Palliative Care Quality Alliance, into a single place. It will collect program-level data on structure and process as well as patient-level data. More information about the collaborative is available at https://palliativequality.org/.

Additional Resources

American Academy of Hospice and Palliative Medicine (AAHPM) offers access to its peer-reviewed journal and other publications, connections among members, and continuing education opportunities, among other resources. More information about AAHPM is available at http://aahpm.org/.

Center to Advance Palliative Care (CAPC) offers comprehensive toolkits on many aspects of palliative care, including separate toolkits specific to designing and growing inpatient, home-based long-term care or clinic-based palliative care programs, as well as continuing education credits for pain management, communication skills, and more. More information on CAPC's full list of toolkits is available at https://www.capc.org/toolkits/funding-a-palliative-care-program/.

National Palliative Care Research Center focuses on developing and funding research to improve care for seriously ill patients. It offers a grants program to fund research and provides webinars and workshops on research methods. More information is available at http://www.npcrc.org/.

Palliative Care Playbook for Hospices is available to NHPCO members and includes information on needs assessment, business case examples, legal and regulatory considerations, quality and data, staffing, budgets, and reimbursement, and more. More information is available at https://www.nhpco.org/playbook/.

Palliative Care Measure Menu is intended for palliative care professionals to simplify the task of reviewing possible measures to assess the quality of a palliative care program. The measure menu is available at https://www.chcf.org/publication/palliative-care-measure-menu/.

Respecting Choices is a resource focused on person-centered care that offers a variety of certifications and education on advance care planning. More information can be found at https://respectingchoices.org/.

Appendix A: Workgroup Subcommittee Members

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Appendix B: Program Profile Contributors

All participants in this whitepaper project were invited to submit a program profile. The following organizations provided information about their knowledge of or work with specialty palliative care programs for the profile. This is an acknowledgement of their input but does not serve as an endorsement of any program.

Ascension Borgess Hospital

Beaumont Hospital—Royal Oak

Covenant HealthCare

Karmanos Cancer Institute

Munson Healthcare/Cowell Family Cancer Center

National Association of Social Workers—Michigan

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