Interaction of Palliative Care and Primary Care

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KEYWORDS

- Primary palliative care • Specialty palliative care • Referral

KEY POINTS

- Primary palliative care assessment includes a symptom assessment, assessing for moderate-to-severe distress, concerns regarding decision-making, and advance care planning.
- Advanced care planning and discussions about dying and palliative care in the outpatient setting by the PCP can improve end-of-life care outcomes.
- Shared decision-making has emerged as an ideal balance between respecting the patient's autonomy to make decisions, and the recognition of the clinician's medical expertise.
- Referral criteria algorithms are available for specialty palliative care referrals.

INTRODUCTION

Scope and Definition of Palliative Care

Palliative care is often believed to be synonymous with end-of-life care or required only after standard care interventions have failed to achieve a desired effect. In fact, earlier palliative care interventions have been shown to potentially increase quality of life, decrease cost of care, and improve survival of patients with metastatic cancer.[1] In 2001, standardization of palliative care with the goal of improving quality of care resulted in the formation of the National Consensus Project for Quality Palliative Care.

In 2009, the Accreditation Council for Graduate Medical Education recognized hospice and palliative medicine (HPM) as a subspecialty, and fellowship training for physicians is required to become HPM board eligible. Comparable certifications for nurses[2] and social workers[3,4] working in palliative care are also newly established

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or being developed. Accordingly, hospice programs and specialty palliative care programs have seen substantial growth[5,6] and increasingly, patients can receive palliative care services in outpatient settings, emergency and critical care departments, and acute care settings.[7]

The definition of palliative care by the Center to Advance Palliative Care (CAPC) is "focused on providing patients with relief from the symptoms, pain, and stress of a serious illness-whatever the diagnosis or prognosis. The goal is to improve quality of life for both the patient and the family." Furthermore, according to American Society of Clinical Oncology Provisional Clinical Opinion, palliative care is "focused on relief of suffering, in all of its dimensions."[1] Palliative care management focuses on symptom assessment and control while emphasizing honest and open communication with families and discussion of appropriate goals of care, especially in patients with advanced illness or significant symptom burden.

Why Primary Care Physicians Should Be Familiar with Palliative Care Approaches

Demand for palliative care specialists is growing rapidly and the number of providers may soon fall short of such demand. In 2008, a workforce task force was appointed by the American Academy of Hospice and Palliative Medicine to perform a needs assessment. The task force concluded that there were approximately 4400 HPM specialists available, whereas an estimated 4487 hospice and 10,810 palliative care physicians are required to staff current hospice and hospital-based palliative care programs. Current fellowship programs have the capacity to train approximately 180 HPM physicians annually. Taking into account the rate of retiring physicians, specialists in palliative care will most likely be unable to fill the annual need for replacement in even the lowest estimate-of-need scenario.[8]

Solutions to the deficiency of HPM physicians are needed to create a more sustainable model. One important strategy is to partner with primary care physicians (PCP) to address basic aspects of palliative care called primary palliative care.

Primary palliative care includes basic skills and competencies possessed by all physicians irrespective of specialty, whereas specialty palliative care includes secondary palliative care and tertiary palliative care. Secondary palliative care is provided by specialist consultants, whereas tertiary palliative care is provided at tertiary medical centers where specialists care for the most complex cases and where clinical care, research, and educational palliative care practices exist simultaneously. In contrast to primary palliative care, specialty palliative care includes managing complex or refractory symptoms and facilitating communication in challenging situations.[9]

Primary palliative care skills consist of elements that are at the heart of palliative care, including basic symptom management, aligning treatment plan with patient goals, and addressing patient suffering. By exercising primary palliative care skills, PCP strengthens existing therapeutic relationships, whereas referring to specialist palliative care services for all basic symptom management and psychosocial support may further fragment care.

Objectives for Primary Palliative Care in the Primary Care Setting

PCP are often the first medical provider patients seek out and are therefore in an excellent position to identify patients who are in need of primary or specialty palliative care services. Many PCP have worked with patients and families for many years and have the added benefit of well-established relationships. PCP are thus well positioned to identify patients that may benefit from early palliative strategies and to provide such care concurrently with life-prolonging interventions. Primary palliative care evaluation can include performing a symptom assessment, assessing for moderate-to-severe distress, addressing concerns regarding decision-making, and assisting with advance care planning.[10] Symptom assessment includes reviewing the more common symptoms and their impact on daily life as shown in **Table 1**. Important decision-making steps can be explored and should be triggered by changes in the disease state: when disease worsens, prognosis changes, after recent hospitalizations, or performance status declines. Useful questions include whether patients have a living will or advanced directive, explaining the benefits and risks of cardiopulmonary resuscitation, and identifying a medical decision-maker who would act on behalf of the patient's wishes.

PRIMARY PALLIATIVE CARE SKILL SET

Symptom-Based Management

PCPs are often the first called on to manage patients' basic symptoms. Therefore, completing a symptom assessment and learning the basic principles of symptom management are essential tools in a physician's tool box.

For example, chronic pain is a symptom that results in significant suffering and economic cost[11–13] and has been increasingly seen as a top national health priority.[14] After maximizing nonopioid pain medications, treatment of chronic severe pain may include the use of opioid medications. Another common symptom is depression. Depression in the outpatient setting is common and has impact on the patient's and family's suffering and quality of life. For outpatients, one or two screening questions can have greater than 80% sensitivity.[15–17] The sole screening question, "Are you depressed?" has been shown in cancer survivors to have a high negative predictive value, so screening for depression need not be an arduous time-consuming evaluation.[15,16]

Other disease- or treatment-related symptoms include nausea, fatigue, intestinal obstruction, and pain from bony lesions. Metoclopramide, haloperidol, or olanzapine can be used for cancer-related nausea[18]; American ginseng can improve fatigue[19]; and referral for radiation therapy for patients with pain from uncomplicated nonvertebral bone metastases is advisable.[20] Please refer to the article on symptom management in the older adult elsewhere in this issue for more in-depth discussions.

Performing a Spiritual Assessment

A spiritual assessment is a key part of primary palliative care, and involving spiritual care specialists, such as chaplains, for patients facing multiple comorbid conditions and high emotional burden can improve patient satisfaction.[21] When medical teams

Table 1
Common symptoms to review on symptom assessment

Symptoms	Assess Impact on Daily Life
Pain Tiredness Nausea Depression Anxiety Drowsiness Anorexia Constipation Dyspnea Secretions	1. On a scale from 1 to 10, 10 being the most severe [symptom], how would you rate your [symptom] right now? At its best? At its worse? What is a tolerable level for you? 2. How much impact does the [symptom] have on your daily life? 3. How bothersome is the [symptom]?

address spiritual care, patients with terminal illness are five times more likely to use hospice and have better quality-of-life scores.[22] A simple assessment tool is the Faith, Importance, Community, Address tool (**Box 1**),[23] or simply ask "Is religion or spirituality important to you?" Community connections to chaplains are essential when referrals are necessary.

Discussions Regarding Advanced Care Planning

Many of the challenges surrounding discussions of advanced care planning in the primary care setting revolve around practitioners' discomfort regarding discussions of death. Concerns revolve around broaching a subject that would cause distress, depression, or destroy hope.[24,25] A recent British study showed that 35% of general practitioners had not initiated a discussion of end-of-life wishes and that 79% agreed that the British public was uncomfortable discussing dying and death.[26] Most Americans want to die at home without pain or suffering, but most die in the hospital undergoing aggressive care.[27,28]

Advanced care planning and discussions about dying and palliative care in the outpatient setting by the PCP can improve end-of-life care outcomes. It is particularly important to convey prognosis accurately, because studies have shown that patients already tend to have an optimism bias toward the curative efficacy of palliative treatments.[29,30] Physicians similarly have been found to be overly optimistic in their prognostication.[31] Given these inherent societal and clinical challenges to discussing prognosis and death, greater comfort and skills regarding these difficult conversations can help counter these inherent biases.

Failure to accurately prognosticate can lead to poorer patient outcomes, such as underuse of hospice care, or underuse and overuse of appropriate preventative screening. Poor prognostication leads to delays in advanced care planning and conversations surrounding death. Many physicians do not feel comfortable prognosticating and studies have shown that physician prognostic accuracy can be poor.[32] One study showed that only 20% of predictions were accurate, overestimating survival by a factor of 5.3.[31] The discomfort physicians feel about prognostication is evident in conversations because prognosis is rarely discussed during these conversations.[33] Despite this, one study showed that 87% of surrogates still wanted physicians to discuss prognosis even if uncertain. Surrogates prefer this primarily because they understand that prognostic uncertainty is unavoidable, and that physicians' are

Box 1
Example questions for the Faith, Importance, Community, Address spiritual assessment tool

Faith	• "Do you come from a particular faith or spiritual background?" • "What things give you a sense of meaning in your life?"
Importance	• "Is your faith or spirituality important to you?" • "Do your beliefs play a role in your health?"
Community	• "Are you part of a faith or spiritual community?" • "Is there a group of people who are very important to you?"
Address	• "How can we help address your spiritual needs?"

Data from Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA tool for spiritual assessment. J Pain Symptom Manage 2010;40(2):163–73; with permission.

their only source of this important information, which is important for preparation of the bereavement process.[32]

Prognostic indices have been developed to help predict overall mortality in various patient groups, although there are limitations to many of them.[34] One such index is ePrognosis (eprognosis.ucsf.edu), which has been validated for use in predicting post-hospital mortality in older adults.[35] This index makes predictions based on such factors as functional status, comorbidities, and laboratory measures, such as creatinine.

Shared decision making has emerged as an ideal balance between respecting the patient's autonomy to make decisions, and the recognition of the clinician's medical expertise, which the patient should be given the opportunity to benefit from. Conversations surrounding advanced planning and palliative care should balance the patient's goals and values with the physician's understanding of the clinical situation and prognosis.

In American medicine today, many physicians are hesitant to provide recommendations because of concerns of infringing on a patient's autonomy. This fails to recognize that often patients want and require recommendations to make an informed decision.[33] Indeed, the American Medical Association and other leading ethical organizations state that providing professional recommendations is a necessary element to autonomous decision making.[36,37] Studies have shown that patients and surrogates vary in the degree of support they want to make regarding end-of-life decisions. One study showed that 56% of surrogates preferred to receive a recommendation and 42% preferred not to.[38] This variation highlights the need to ask patients early on in the conversation how they prefer to receive their information, how much information they desire, and whether they would like to hear the physician's recommendation.

An important first step is to establish an appropriate private setting and environment for these conversations. If possible, ensure that there is sufficient time for the conversation while minimizing potential interruptions. Ask if family members or others should be present, and ensure that all are comfortable. Conversations should subsequently begin with an elicitation of the patient's understanding of their illness and prognosis, and clarification of accurate clinical information where necessary. Subsequent discussion should focus on the patient's expectations, goals, and values. If you perceive the patient's expectations and hopes to be overly optimistic, this is a good time to clarify and manage expectations. At this time, the physician can state their recommendation for the best course of action, and together with the patient, establish a consensus on the best plan.[39]

In general, the physician should listen carefully, remain empathetic, and be responsive to emotions to establish the trust necessary for a productive, respectful conversation.[25,40] Questions should be open-ended and nonjudgmental. In one study comparing expert internists in communications or bioethics with the average physician, experts spent twice as much time listening and were less verbally dominant. The expert physicians gave less information but spent more time building partnerships and asking psychosocial and lifestyle questions.[41]

Resuscitation status and the initiation of a do-not-resuscitate order is an important element of this goals of care conversation, although physicians must also be careful to recognize that resuscitation is but one component of a series of important decisions that must be made.[42] Such forms as the Medical Order for Life Sustaining Therapies and Physician Order for Life Sustaining Therapies recognize the need to expand the focus of end-of-life conversations beyond resuscitation.[43] Furthermore, it is important to recognize that although advanced care planning is important, it is an imperfect tool that must be readdressed and recrafted through time. A patient's preferences can change depending on the circumstance so it is important that these advanced planning decisions are reviewed frequently and are responsive to change.[40]

Continuing Relationships with Patients After Referral

If patients do ultimately require specialty palliative care referral, maintaining and emphasizing the primacy of the relationship between PCP and patient is important for continuity of patient care. Regular communication between teams is essential to providing care consistent with patient goals and wishes, to coordination of care, and to avoid redundancy.[44,45]

When to Refer to Specialty Palliative Care Services

Referral criteria algorithms are increasingly being used as a means of identifying patients in need of referral for specialty services.[46] Variables, such as disease state, severe symptoms, and psychosocial emotional impact of illness, are included in decision algorithms.[1,47]

Referral in the Inpatient Setting

The consultation service is the most common form of palliative care service delivery in acute care hospitals. Difficult-to-manage symptoms, complex family dynamics, and challenging care decisions regarding the use of life-sustaining therapies are all reasons to consider specialty palliative care.[48–51] In 2008 to 2010, CAPC compiled a list of suggested triggers for in-patient palliative care consultation services.[52–54] Key principles from the consensus statement stress the following: specialty-level palliative care professionals should be used in complex cases, every hospital should develop a systematic approach to ensure that patients who require but have unmet palliative care needs are identified and supported in a timely fashion, patients should undergo a screening for palliative care assessment as part of day-to-day care, and hospitals should have a specialty-level palliative care service available. **Fig. 1** summarizes

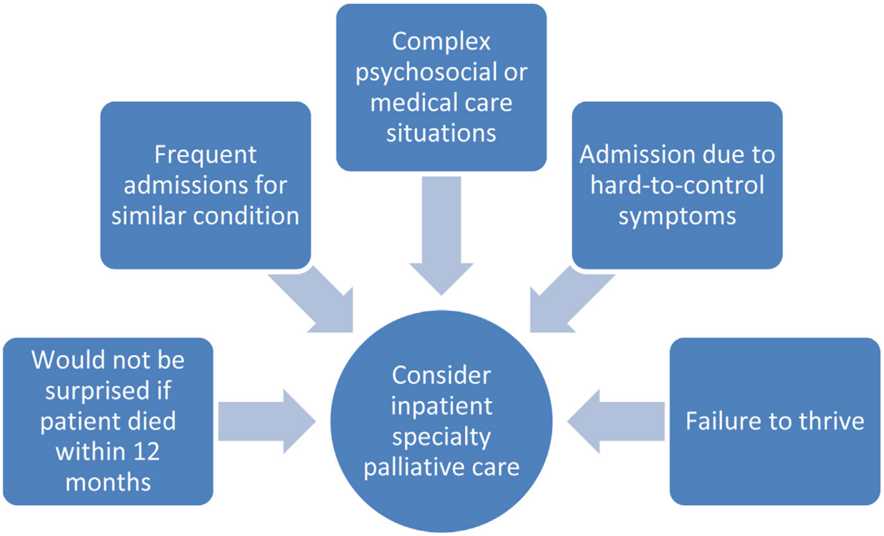

Fig. 1. Criteria for considering palliative care assessment at the time of hospital admission. (*Data from* Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. J Palliat Med 2011;14(1):17–23.)

triggers from the CAPC Consensus Report for medical providers to consider consulting specialty palliative care at the time of hospital admission.[46]

Referral in the Outpatient Setting

A wide variety of models for palliative care exist for patients seeking palliative care services in the outpatient setting. However, outpatient palliative care programs are relatively infrequent, small,[55] affiliated with cancer centers, and have varied availability from half-day per week to 5 full days weekly.[56] Studies regarding which outpatient palliative care model is best remain ambiguous but clinical practice guidelines do exist.[57] Much of the same criteria for inpatient referrals can be extrapolated to palliative care consultation in the outpatient setting. In inpatient and outpatient settings, palliative care is ideally provided by an interdisciplinary team, which may include physicians, mid-level providers, social workers, nurses, spiritual care, rehabilitation medicine, nutrition, and other health professionals.[58] In fact, inclusion of social workers greatly facilitated completion of advance directives in one study.[59]

Three models exist for outpatient palliative care services. The first is a consultation model: recommendations are conveyed to the primary team but the palliative care team does not prescribe medications. The second is an embedded or integrated palliative care model. This is a collaborative model where the palliative care team takes the lead in managing symptoms while other physicians manage disease-modifying therapy.[60] In this model, communication between teams is essential to provide consistent management plans to the patient and avoid mixed messages. The third and final model is one where the palliative care team takes over all aspects of care including diagnosis, management, and prescriptions for all health issues, including the disease that triggered a palliative care referral. Care in this model is not common but may be the favored strategy for patients who decline curative antineoplastic treatment or may not be eligible for such therapies. Patients may or may not be simultaneously enrolled in hospice services and care may be provided in many settings including the home, nursing home, or care facility.[59]

Outpatient palliative care consultation visits may be lengthy, ranging from 60 to 120 minutes.[56,61,62] The content of an outpatient palliative care visit depends on the reasons for referral, the patient, and the palliative care providers. In addition to the standard history and physical, the typical palliative care assessment includes the domains shown in **Box 2**.[44]

When to Consider Hospice Referral

When patients have 3 to 6 months to live, an informational hospice referral should be made.[1] Indicators of 6-month mortality in advanced noncancer illnesses vary by disease and can facilitate the practitioner in initiating goals of care discussions with the patient.[63]

Patients with nonmalignant conditions but with high burden of disease may be a challenge in estimating life expectancy. Prognostic uncertainty and lack of evidence concerning efficacy of treatments in far advanced disease may add to general practitioners' uncertainty regarding patients requiring palliative treatment strategies. A screening question for identifying patients who may benefit from palliative strategies includes asking, "Would I be surprised if my patient were to die in the next 12 months?"[64] Tools exist to predict survival of less than or equal to 6 months for patients with and without cancer.[63,65] Decline in performance status, weight loss or anorexia, and any malignant effusion should all trigger consideration for hospice.

Box 2
Domains of palliative care assessment

Physical symptoms	• Pain, nausea, fatigue, cough, constipation, dyspnea, insomnia, depression, anxiety, issues with intimacy, and so forth
Psychosocial	• Preferred way of coping, cultural issues, education/employment, impact of illness, significant relationships, sources of stress and support
Assistance with practical needs	• Living situation, caregiver needs, financial issues, access to health care, transportation, nutrition
Spiritual care	• Faith, importance of spirituality, connection to faith community, need to address spirituality in context of medical care
Support for decision making	• Discuss and facilitate advance care planning, goals of and preferences for care • End-of-life care

Data from Von Roenn JH, Temel J. The integration of palliative care and oncology: the evidence. Oncology (Williston Park) 2011;25(13):1258–60, 62, 64–5.

To receive Medicare hospice benefit, a PCP and the hospice medical director must certify that the patient has an expected prognosis of 6 months or less, based on documented criteria that vary depending on illness. In general, there should be progression of disease as evidenced by symptoms, test results, or imaging. The Medicare hospice benefit provides end-of-life care to terminally ill patients and their families and hospice eligibility guidelines were extended to those dying of noncancer diagnoses, including geriatric diseases, such as advanced dementia, and cardiovascular disease. Adult failure to thrive was a Medicare-supported hospice diagnosis until October 1, 2014.[66] A high-quality hospice program is usually Medicare certified, with staff trained in HPM; offers medical, nursing, social work, bereavement, and spiritual services; and engages in patient- and family-centered care.[67]

For many within the medical field, hospice is synonymous with specialty palliative care services. The primary goals of both groups are similar: to maximize quality of life, provide pain and symptom management, and provide psychosocial and spiritual support via an interdisciplinary team approach for patients and their families. The PCP often continues to provide overall medical care for hospice and palliative care patients while a hospice medical director and palliative care specialist provides expertise in disease-related symptom management.

Hospice services and specialty palliative care differs in that palliative care services may be delivered concurrently with curative or life-prolonging therapies, whereas with hospice enrollment, patients are choosing hospice care instead of other Medicare-covered benefits to treat their terminal illness.[67] This distinction, however, is evolving. The passage of the Patient Protection and Affordable Care Act of 2010 added new provisions allowing children access to hospice and curative care under the Children's Health Insurance Program[68] and establishing a 3-year Medicare hospice concurrent care demonstration program.

Ultimately, referrals to hospice must be in line with a patient's goals of care. When all available options are presented and not just the next step in medical management, discussions lead naturally to patient- and family-centered goals and quality of life. Drawing connections between patients' goals and services provided by hospice makes these conversations easier.[69]

SUMMARY

With ever-increasing demand for HPM physicians, primary care providers serve an integral role in providing primary palliative care. Primary palliative care skills, such as completing basic symptom and spiritual assessments and managing common symptoms, are essential in caring for the geriatric population, as is having competency in basic advanced care planning discussions. Specialty palliative care provides an extra layer of support for patients and PCP in managing refractory symptoms and navigating complex goals of care discussions. Knowing when to refer patients to palliative care and hospice services is important in maximizing their quality of life and providing aggressive symptom management throughout the entire disease course. The relationship between primary care and specialty palliative care will undoubtedly continue to grow and evolve and will continue to benefit patients and their caregivers.

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