Understanding Palliative Care and Hospice: A Review for Primary Care Providers

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CME Activity

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Abstract

Palliative care provides invaluable clinical management and support for patients and their families. For most people, palliative care is not provided by hospice and palliative medicine specialists, but rather by their primary care providers. The recognition of hospice and palliative medicine as its own medical subspecialty in 2006 highlighted the importance of palliative care to the practice of medicine, yet many health care professionals harbor misconceptions about palliative care, which may be a barrier to ensuring that the palliative care needs of their patients are identified and met in a timely fashion. When physicians discuss end-of-life concerns proactively, many patients choose more comfort-focused care and receive care more aligned with their values and goals. This article defines palliative care, describes how it differs from hospice, debunks some common myths associated with hospice and palliative care, and offers suggestions on how primary care providers can integrate palliative care into their practice.

WHAT IS PALLIATIVE CARE?

Unlike other medical specialties, the field of palliative care does not address the underlying disease process. Palliative care addresses symptoms directly to improve how the patient feels, regardless of the cause. As defined by the Center to Advance Palliative Care:
Palliative care, also known as palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.¹

Specialty palliative care uses an interdisciplinary team to fully address the needs of patients and families. Nurse practitioners, nurses, social workers, chaplains, and pharmacists work alongside physicians to address psychosocial and spiritual concerns of patients and families in addition to physical symptoms. Symptom management, psychosocial-spiritual support, and facilitation of medical decision making are 3 key domains of palliative care. The Table describes common elements of palliative care in each of these domains. Even with tremendous growth in the past 2 decades, including recognition of hospice and palliative medicine (HPM) as an official subspecialty of the American Board of Medical Subspecialties and the American Osteopathic Association, there remains a shortage of HPM specialists, which is projected to increase as the population ages.² Thus, most palliative care is, and arguably should be, provided by non-HPM specialists, including internal medicine, family physicians, and nurse practitioners.³ Primary care providers (PCPs) are particularly well-suited to deliver primary palliative care. The development of team-based primary care, such as the patient-centered medical home,⁴ and the incorporation of population health principles into restructuring primary care should improve outcomes relevant to palliative care.

Palliative care is not well understood by patients or clinicians. A recent Center to Advance Palliative Care⁵ survey found that 70% of Americans were “not at all knowledgeable” about palliative care. This lack of awareness creates an opportunity for clinicians to frame the benefits of palliative care for patients and their families. Yet the survey also found that most health care professionals erroneously equated palliative care with end-of-life (EOL) care. Clinicians who perceive palliative care as EOL care, or lack a clear understanding of its benefits, will miss critical opportunities to identify and address palliative care needs in their patients. Primary palliative care competencies for PCPs include (1) recognition of palliative care needs in patients, (2) prognostication, (3) advance care planning, (4) assessment and management of common symptoms in the seriously ill, (5) referral to specialty palliative, and (6) appropriate and timely referral to hospice.

### RECOGNIZING PALLIATIVE CARE NEEDS IN PRIMARY CARE PATIENTS

Patients with a serious illness often experience substantial physical burden due to pain and symptoms such as fatigue, anorexia, nausea, and dyspnea. Anxiety and depression are also common after the diagnosis of a life-threatening illness. Any of these symptoms may alter a person’s ability to fulfill roles critical to self-identity, such as athlete, caring spouse, or devoted parent. Through their longitudinal relationship, PCPs can help individuals explore these issues and find ways to adapt and prioritize in the face of a serious illness.

Many PCPs already engage in primary palliative care but may not recognize their actions as palliative care. Primary care providers commonly provide careful assessment of symptoms and recognition of how the symptoms affect that individual’s quality of life. Many also routinely prescribe and titrate opioids for patients in pain.⁶ Primary care providers often focus on maximizing quality of life by helping patients and their families find value and meaning, particularly when a patient’s time or function is limited. It is important to help PCPs gain insight into primary palliative care that they already provide, so they may disentangle palliative care and EOL care and integrate palliative care to meet the needs of their patients. Effective symptom management promotes a patient’s ability to remain active in important activities and relationships. When appropriate, palliative care

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counseling by PCPs can extend to family caregivers during active caregiving and into bereavement.

**PROGNOSTICATION AND COMMUNICATION**

Patients with a serious illness commonly face difficult medical choices. Patients who realize their prognosis is less than a year often elect to avoid more invasive interventions. However, many patients, even after discussions with their doctors, harbor unrealistic ideas about their prognosis and about the likely benefits of medical treatments. Effective communication allows clinicians to assess patients’ informational needs and facilitate clear understanding of their prognosis. A key challenge for PCPs is anticipating palliative care needs in patients before they are in medical crisis. Elderly patients and patients with multiple chronic conditions, but no clear life-threatening diagnosis, can rapidly deteriorate from being spry and independent into a state in which they are too compromised to participate meaningfully in medical decision making. Thus, heightened awareness of patient factors that predict a shortened survival or elevated risks of decline are key palliative care skills. Estimating prognosis is challenging even in illnesses with a defined trajectory, such as malignancy. However, online resources, such as www.ePrognosis.org, may help PCPs determine prognostic estimates, particularly for complex patients. PCPs could also adopt “the surprise question,” which is a simpler strategy to identify patients at high risk for mortality. Clinicians may ask themselves, “Would I be surprised if this patient died in the next year?” A “No” response to this question has been shown to be strongly associated with an increased likelihood of dying within the next year in various populations.

**ADVANCE CARE PLANNING**

As the medical professionals who know their patients best, PCPs are often uniquely suited to help elicit an individual’s personal goals, establish priorities, and facilitate informed medical decisions that reflect the patient’s values. Most PCPs believe that advance care planning is within their purview, but struggle to find adequate time during patient visits and address competing health conditions appropriately. In 2016, the Medicare program began reimbursing clinicians for counseling patients about advance care planning. This was an important step toward supporting clinicians for the considerable time it takes to have these crucial conversations. More deliberate prognostication efforts may help PCPs identify their patients for whom advance care planning is a priority.

Advance care planning includes encouraging patients to appoint a health care proxy or surrogate decision maker, facilitating discussions between the patient and their proxy about their wishes in the event of serious illness, and documenting these discussions. Importantly, most patients want information about prognosis in the setting of serious illness. Given the established relationship between PCPs and many of their patients, PCPs are best positioned to help patients make informed decisions about their care. Primary care providers who take time to explore a patient’s wishes in light of a life-threatening illness can profoundly influence decisions made and care received near the EOL. Patients who discuss EOL concerns with a physician earlier are more likely to take a comfort-focused approach to care at the EOL. Patients who make their wishes known in advance are more likely to receive care aligned with their preferences. Advance care planning can also improve the mental health outcomes for their family caregivers.

**WHEN TO REFER TO SPECIALTY PALLIATIVE CARE**

There is no evidence to suggest that early integration of palliative care shortens survival. Yet many patients and health care professionals share an unspoken concern that it may hasten death. This common misconception—combined with the misconception that palliative care is equivalent to EOL care—denies patients and families access to palliative care until late in the illness trajectory. Several prospective randomized controlled trials have compared early integration of specialty palliative care with standard care or, in 1 case, later integration of palliative care. These trials, primarily conducted in patients with advanced cancer, have shown improvements in important end points, including patient quality of life, rates of depression or anxiety,
patient or caregiver satisfaction, and utilization of health services at the EOL. Two trials\(^{19,21}\) have also reported longer survival in the early palliative care arm.

The benefits of palliative care for patients with a serious illness are maximized through early integration in the illness trajectory. These benefits are depleted when palliative care is conceived more narrowly as EOL care. This concept of palliative care as “brink-of-death” care clearly deprives patients and families of the benefits observed with earlier integration (Figure).\(^{22}\) Although it has not been established whether the benefits derived from early integration by a specialty palliative care team or from high-quality primary palliative care are equivalent, there are reasons to expect they would be. Primary care providers who remain involved in their patient’s care when being followed by other specialists are uniquely positioned to help with coping, symptom management, and navigating complex decisions so that the specialist may remain focused on providing disease-modifying therapy. Primary care providers may then opt to involve specialty palliative care in patients with refractory symptoms or for patients with anxiety, depression, or poor coping skills that might interfere with decision making.

**REFERRING PATIENTS TO HOSPICE**

Historically, the field of palliative care grew out of the hospice movement, shaping a public misconception that they are synonymous. However, the terms palliative care and hospice should never be used interchangeably. In the United States, hospice is a critical, focused component of palliative care, with specific eligibility requirements driven by the 1983 Medicare hospice benefit. Hospice is usually provided in the patient’s home to allow them to die comfortably surrounded by loved ones. Although fewer than 25% of Americans die at home despite an overwhelming desire to do so, more than 75% of patients on hospice die at home.\(^{\text{23}}\) Thus, hospice is really the service that allows patients to die at home, if they choose to do so.

**WHAT HOSPICE SERVICES PROVIDE**

Hospice is a team-based approach to care. Typically hospice is provided by an interdisciplinary team comprising a nurse, social worker, home health aides, chaplain, volunteers, and hospice medical director. Hospice has 4 levels of care: routine home care, general inpatient care, continuous care, and respite care. Most hospice care (96%) is routine home care, delivered in the patient’s residence to ensure comfort and avoid hospitalization.\(^{24}\) Members of the team visit the patient’s home to assess symptoms, adjust medications to alleviate or mitigate symptoms, and provide support to the patient and family. Hospice covers durable medical equipment, such as a hospital bed, commode, and supplemental oxygen provided in the home as well as the cost of all medications related to the hospice diagnosis, including schedule II opioid analgesics. Finally, patients on hospice may access a hospice provider, usually a nurse, 24 hours a day, 7 days a week by phone. When phone guidance is insufficient, the hospice provider will come to the patient’s home day or night. Reliable, easy access to an expert provider provides comfort and reassurance to family members, who provide the bulk of care to patients, while helping to avoid emergency department visits and hospitalizations. Occasionally, patients on hospice with complex symptoms, such as refractory pain or agitated delirium, do require hospital care. Such patients can remain on hospice under the general inpatient benefit at either an inpatient hospice facility (if available) or a hospital, in which the hospice team visits them daily and continues to manage their care along with the inpatient hospital team. In contrast, the continuous care hospice benefit provides between 8 and 24 hours of medical care, usually nursing.
care, in the patient’s home. The continuous care benefit is typically used to manage a complicated symptom or to allow a patient to remain at home, during a symptom crisis, with ample medical support. The hospice benefit will also provide up to 5 consecutive days of respite care in a facility, often a skilled nursing facility, to relieve stress of family caregivers. In 2012, continuous care and respite care combined accounted for less than 1% of hospice care delivered in the United States.24

When starting hospice, patients choose a primary physician, often their PCP, to oversee their medical care while on hospice. This physician receives updates and changes in the patient’s status and gives orders for medications as needed. Many patients fear abandonment by their regular providers when hospice is mentioned. By reassuring their patients that they will remain the physician in charge of their care, PCPs can mitigate this concern. Moreover, able patients on hospice can continue to come in for clinic visits with their PCP and other providers if they desire. However, most hospice benefits do not cover hospitalization unless required for a patient’s comfort. In general, hospitalization requires that patients disenroll from hospice and resume prior insurance. Approximately 3% to 6% of patients enrolled in hospice get hospitalized, and many of these patients go on to receive high-intensity care, which indeed may conflict with their preference for comfort measures.25,26

LIMITATIONS OF HOSPICE
To qualify for hospice care, a physician must certify that the patient is expected to die within the next 6 months, if the disease follows its natural course. Once enrolled in hospice, a physician or hospice nurse practitioner must have at least 1 face-to-face visit with the patient in each of the first two 90-day periods, which certifies that the patient continues to meet the prognostic criteria. Patients surviving longer than 6 months require recertification once every 60 days, also accomplished through a face-to-face visit.27 Occasionally, patients recover unexpectedly and no longer qualify for hospice. Such patients, often dubbed “hospice graduates,” disenroll from hospice and resume their prior medical care. Patients often qualify for hospice before actually being referred. This is partially because physicians notoriously overestimate prognosis,28 but is also related to readiness of patients and their families to accept hospice. Primary care providers engaged in primary palliative care may help prepare patients and their families for an earlier transition to hospice.

The other major distinction in hospice care is that because of the reimbursement structure, hospice is required only to provide comfort-focused care related to the hospice diagnosis. The Medicare hospice benefit requires patients to forgo treatments aimed at curing their terminal diagnosis. Thus, many hospices will not accept patients receiving disease-directed care (eg, chemotherapy for cancer) because they will not be reimbursed for these therapies, even when the intent is palliative. Such treatments can delay referral to hospice while perpetuating the misconception that hospice is only for the final days of life. Some “open access” hospices allow patients to continue on disease-directed therapy, but this is negotiated on a case-by-case basis. Although receipt of hospice care has increased in recent years, the proportion of patients enrolling within 7 days has also increased.29 Such late enrollment in hospice deprives patients and families of the chance to derive optimal benefits from hospice services30; timely referral to hospice is key to ensuring patients and families can take advantage of hospice benefits.

OVERCOMING BARRIERS TO HOSPICE USE
Even among patients and health care professionals who understand the value of hospice, many still equate hospice to “giving up” and/or agreeing to shorten one’s life. Reframing hospice as a choice to focus on how one lives rather than how long one lives sometimes can help patients and families accept hospice. Interestingly, care focused on comfort and quality may allow patients to live both better and perhaps a little longer.31

When choosing hospice, most patients will also choose to forgo attempts at cardiopulmonary resuscitation (CPR), but a do-not-resuscitate order is not required. Patients who wish for comfort-focused care but, for some reason, still want the option for attempted resuscitation can be enrolled in hospice. The hospice team will continue to address
the issue of code status with the patient and family. Once patients understand the likely outcome of CPR, many choose to forgo it. It is important to highlight the services hospice does provide and not overemphasize the interventions, such as CPR, which are incongruous with hospice goals.

SUMMARY

The prevalence of progressive chronic illnesses is increasing. The medical community is recognizing the importance of prioritizing medical treatments that promote quality of life along with interventions primarily aimed at prolonging survival. The expansion of primary palliative care delivered by PCPs will greatly promote symptom management and quality of life for patients throughout the course of a life-threatening illness, not just at the end. The development of new models of integrated palliative care will allow patients and families to consider their own personal goals and quality of life when making choices about the direction of their medical care. When attuned to patients’ personal values, primary care providers can help individuals find meaning and joy when living with limited function and/or shortened life expectancy.

Abbreviations and Acronyms: CPR = cardiopulmonary resuscitation; EOL = end of life; HPM = hospice and palliative medicine; PCP = primary care provider

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