

Top 10 Things Palliative Care Clinicians Wished Everyone Knew About Palliative Care

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CME Activity

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Abstract

With a focus on improving quality of life for patients, palliative care is a rapidly growing medical subspecialty focusing on the care of patients with serious illness. Basic symptom management, discussions of prognostic understanding, and eliciting treatment goals are essential pieces in the practice of nearly all physicians. Nonetheless, many complex patients with a serious, life-threatening illness benefit from consultation with palliative care specialists, who are trained and experienced in complex symptom management and challenging communication interactions, including medical decision making and aligning goals of care. This article discusses the changing role of modern palliative care, addresses common misconceptions, and presents an argument for early integration of palliative care in the treatment of patients dealing with serious illness.

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1. PALLIATIVE CARE CAN HELP ADDRESS THE MULTIFACETED ASPECTS OF CARE FOR PATIENTS FACING A SERIOUS ILLNESS

Palliative care is specialized medical care focused on identifying and relieving the pain and other symptoms of a serious illness. Its goal is to improve quality of life for such patients at any stage of illness regardless of current treatment plans, and it is tailored to the needs of the patient and the family. Given that patients and their illnesses do not exist in a

vacuum, palliative care is meant to be an active and comprehensive form of medical care that targets the physical, emotional, and social aspects of a patient's disease experience.¹ Understanding how illness affects patients' lives, both mentally and physically, is a critical aspect of a palliative care evaluation.

Adhering to this philosophy of patient- and family-centered care requires an interdisciplinary team of health care professionals, including physicians, nurses, advanced-practice clinicians (eg,



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nurse practitioners and physician assistants), social workers, chaplains, and pharmacists. Access to palliative care is rapidly growing and is available for many patients with a serious illness. More than 85% of US hospitals with 300 or more beds have palliative care consultative services,² and such services are federally mandated in all Department of Veterans Affairs medical centers.³ As this subspecialty grows, it is important for referring clinicians to understand the scope, timing, and misconceptions about palliative care referrals.

2. PALLIATIVE CARE IS APPROPRIATE AT ANY STAGE OF SERIOUS ILLNESS

Early models of palliative care's role conveyed both an ideologic and a chronologic separation between life-prolonging care (eg, chemotherapy and hemodialysis) and palliative care. Palliative care was often errantly equated with only providing end-of-life care. In practice, this led (and unfortunately still leads) to palliative care involvement occurring late in an illness when such disease-modifying interventions are either no longer an option or no longer desired by the patient.

In fact, the goals of palliative care, such as improving quality of life through comprehensive symptom management and patient and family support, are ideally applied *throughout* the trajectory of a serious illness. An intensive focus on symptom management, psychosocial support, and attention to advance care planning provided by early palliative care integration has benefits for patients, families, and fellow caregivers. Conversely, there is a growing recognition that increased intensity of invasive interventions in late stages of illness does not necessarily prolong survival or reliably improve quality of life.⁴ In addition, there is now convincing evidence that early integration of palliative care, including active symptom management, provided concurrently with disease-modifying care can improve quality of life, minimize such invasive interventions, and potentially have a measureable mortality benefit.⁵⁻⁷

3. EARLY INTEGRATION OF PALLIATIVE CARE IS BECOMING THE NEW STANDARD OF CARE FOR PATIENTS WITH ADVANCED CANCER

Support for an expanded and upstream role for palliative care is well supported by recent data

from the oncologic literature, in which well-designed studies have found that early integration can lead to more optimal clinical outcomes than prior archetypes of late-stage involvement.^{5,8} A recent landmark phase 3 randomized controlled trial reported that early involvement of palliative care at the time of initial diagnosis in patients with advanced non–small cell lung cancer undergoing disease-targeted therapy led to improved outcomes in terms of quality of life, mood, and less aggressive interventions at the end of life.⁵ Notably, patients in the palliative care arm lived 2.7 months longer than patients in the standard care arm, a statistically significant and unanticipated outcome. When involved early in the disease course, initial palliative care visits focused on symptom management and prognostic awareness, with goals of care discussions gaining added importance later in the disease course.⁹

On the basis of these and other findings, in 2012, the American Society of Clinical Oncology recommended that palliative care be integrated early in the illness for patients with metastatic cancer and/or high symptom burden.¹⁰ Similarly, the National Comprehensive Cancer Network has recommended that institutions develop processes to integrate and offer palliative care in conjunction with disease-modifying therapies and that patients be screened at regular intervals to assess for benefit of palliative care involvement.¹¹ International bodies, such as the World Health Organization, advocate early involvement of palliative care in tandem with therapies intended to prolong life, describing palliative care as an essential part of cancer control.¹² The new standard of comprehensive oncologic care includes the integration of early palliative care provided alongside cancer-targeted therapy.

4. MOVING BEYOND CANCER: PALLIATIVE CARE CAN BE BENEFICIAL FOR MANY CHRONIC DISEASES

Although palliative care is increasingly integrated into contemporary cancer care, barriers to involving palliative care into the care of non-oncologic patients with a serious illness remain. Patients with severe chronic obstructive pulmonary disease (COPD), advanced congestive heart failure (CHF), pulmonary hypertension, end-stage renal disease, and neurodegenerative diseases (eg, amyotrophic lateral sclerosis and

Huntington disease) have a heavy symptom burden.¹³⁻¹⁶ These patients, along with those with critical illness in intensive care units, may benefit from palliative care involvement in aggressive symptom management, psychosocial and spiritual support, shared decision making, continuity of care, and staff support.¹⁷ This benefit is increasingly recognized by a variety of specialty societies calling for early palliative care integration.^{10,18,19}

5. PALLIATIVE CARE TEAMS MANAGE TOTAL PAIN

Pain among cancer patients is well described, affecting 30% to 60% of patients receiving active, cancer-directed treatment and 70% to 90% of those with advanced-stage disease.^{20,21} Functional status and quality of life are significantly affected by inadequate treatment of pain. Despite the known prevalence and effect of cancer pain, it is often undertreated, with one review suggesting that 43% of cancer patients receive suboptimal analgesia.²²

Although cancer-related pain is a well-known entity among clinicians, incidence of pain in patients with other serious illnesses is often underappreciated. More than 50% of patients with advanced COPD and up to 85% of patients with severe CHF have pain symptoms, and approximately one-third of these patients have severe pain.^{14,23} Half of all patients with diseases as different as amyotrophic lateral sclerosis and end-stage renal disease undergoing hemodialysis have undertreated pain.^{15,16,24}

Palliative care clinicians have training and expertise in the management of pain syndromes associated with chronic and severe illness. Experienced with the use of opioids and non-opioid adjuvants, palliative care clinicians are well versed in management of pain using a broad array of pharmacologic and nonpharmacologic therapies. With active surveillance and treatment, most patients with a serious illness can obtain effective analgesia.²⁵

Many institutions have access to the expertise of interventional pain clinicians, and there can be uncertainty as to which service to involve for a given patient with pain. Palliative care clinicians may be most helpful when dealing with pain in the setting of a serious or life-threatening illness or when there are concomitant nonpain symptoms that affect that patient's experience

of pain (eg, nausea, anxiety, and depression). In addition, given that many patients face complex psychosocial and spiritual issues related to their serious illness and its fluctuations, palliative care teams are well placed to address what Dame Cicely Saunders described as "total pain," defined as physical, social, psychological, and spiritual suffering.²⁶ At our respective institutions, palliative care and pain management teams often collaborate on challenging cases. Palliative care clinicians can also help identify and refer patients for interventional pain therapies, such as intrathecal drug delivery or neurolytic blocks for refractory cancer pain, and assist in weighing goals of care of such interventions.

6. PATIENTS WITH A SERIOUS ILLNESS HAVE MANY SYMPTOMS THAT PALLIATIVE CARE TEAMS CAN HELP ADDRESS

Many patients with chronic and severe illness endure many nonpain symptoms.²⁵ Nausea is a distressing symptom that affects as many as 70% of patients with advanced cancer and up to 50% of patients with noncancer diagnoses, such as CHF, COPD, and renal failure.²⁷ Delirium occurs in up to 85% of terminally ill cancer patients.²⁸ Delirium can not only affect the quality of life of patients but can also have a lingering emotional effect on family and caregivers.^{29,30} Fatigue affects two-thirds of patients with advanced CHF,¹³ more than 70% of patients with advanced COPD,¹⁴ and 80% of cancer patients receiving chemotherapy and/or radiotherapy.³¹ Dyspnea affects up to 90% of patients with end-stage lung disease,¹⁴ 70% of patients with cancer,³² nearly half of patients with end-stage renal disease,³³ and more than 60% of patients with end-stage CHF.³⁴ Experienced with management of such nonpain symptoms, palliative care clinicians can not only help identify and address the many symptoms that affect a patient's quality of life during an illness but can also ameliorate the effect those symptoms have on caregivers.

7. PALLIATIVE CARE CAN HELP ADDRESS THE EMOTIONAL IMPACT OF SERIOUS ILLNESS ON PATIENTS AND THEIR FAMILIES

Psychological distress is common among patients with a serious illness and is strongly correlated with impaired quality of life.³⁵ Importantly, although clinical depression is not a

normal part of the dying process, preparatory grief is experienced by most dying patients. Preparatory grief occurs when people prepare for their death by mourning impending losses, including loss of function, anticipated missed events (such as a child's wedding), and separation from loved ones.^{35,36} Distinguishing between normal preparatory grieving and clinical depression is a substantial clinical challenge, given the similarity of many of the signs and symptoms. Moreover, many of the neurovegetative symptoms we commonly associate with depression are a normal part of severe illness.^{35,36} Palliative care teams can help providers with these essential distinctions, allowing for earlier interventions given that depression is associated with substantial suffering and even decreased longevity, requiring prompt treatment, even in the very late stages of an illness.³⁵

Beyond identification and treatment for depression, palliative care teams work to improve mood through aggressive symptom management, as well as psychosocial and spiritual support. Improving the management of other symptoms, such as severe pain or intractable nausea, can markedly improve a patient's mood, sense of hope, and quality of life.^{35,37} Many patients facing the end of their lives are able to achieve a high degree of equanimity and acceptance of their illness and impending death. Factors that contribute to effective coping and achieving peace include good communication and trust among the patient, family, and clinical team; opportunities for the patient to share fears and concerns; and meticulous attention to physical symptoms and psychological and spiritual concerns.³⁷ The opportunity for patients to share hopes, worries, and what their illness means to them is therapeutic for many patients.³⁷ It is this combination of meticulous attention to both psychosocial distress and physical symptoms that is at the heart of palliative care.

8. PALLIATIVE CARE TEAMS ASSIST IN COMPLEX COMMUNICATION INTERACTIONS

Although emotionally intense conversations with patients with serious illness are part of the everyday work of the palliative medicine practitioner, the importance of excellent communication skills extends to the work of all health care practitioners. This type of patient-centered, empathic communication between patients and physicians has been found to improve patient

satisfaction, adherence to therapy, and health outcomes.³⁸⁻⁴⁰

Strong emotions are a normal response to discussing stressful, life-changing events, such as being sick.^{41,42} Patients' emotions are important pieces of clinical data that can teach us what patients understand about their medical circumstances and what kind of additional support or information they might need. The challenge for all clinicians is to be present with patients and respond to their emotions without trying to "fix" it.^{41,42} Responding to emotion and demonstrating empathy align us with our patients and make them feel heard.⁴² Nonverbal responses to emotion include such actions as leaning forward, moving the chair closer, making eye contact, and handing the family tissues. Verbal responses of empathy include expressions of support, understanding, and respect.^{42,43}

How clinicians respond to these emotions and the words used can have powerful and unintended consequences. Our words are most effective when they are clear and align us with the patient. Phrases such as "there is nothing more we can do" or "withdrawing care" not only damage the patient-provider relationship,⁴⁴ but they also fail to reflect clinical reality. We are always providing care and working to optimize quality of life, regardless of whether or not further life-prolongation is possible. Palliative care clinicians can help reinforce this notion of ongoing care, working with collaborating providers to manage distressing symptoms and support the patient and family, even when life-prolonging therapies are no longer available or desired.

9. ADDRESSING THE BARRIERS TO PALLIATIVE CARE INVOLVEMENT: PATIENTS' HOPES AND VALUES EQUATE TO MORE THAN A CURE

Concerns that a patient "is not ready for palliative care" often center around a worry that palliative care involvement signals a "beginning of the end" and will take away a patient's hope. Patients and their families may echo these concerns and resist meeting with the palliative care team. Yet, data suggest that engaging in discussions about one's illness, wishes, and the benefits and burdens of disease-modifying therapies helps patients make better decisions about the types of health care they wish to receive. In addition,

improved understanding of one's illness and associated prognosis leads patients to make different decisions about the types of care they wish to receive.^{4,45} Furthermore, such discussions do not seem to cause psychological harm and may be associated with improved patient quality of life and family member bereavement.⁴

Although resistance to upstream palliative care involvement can stem from both patients and clinicians, the root of this resistance is often a misunderstanding of the role of palliative care. Public opinion data commissioned in 2011 reveal that almost 80% of respondents lacked knowledge about the role of palliative care. However, many physicians continue to equate palliative care with end-of-life and/or hospice care. After hearing that palliative care is specialized medical care focused on alleviating pain and other symptoms associated with serious illness and that it ideally occurs concurrently with life-prolonging care, more than 90% of respondents believed that patients with a serious illness should be educated about palliative care. Respondents also believed that palliative care should be available alongside curative-intent therapies and is appropriate at any age and any stage of illness.⁴⁶

In considering the growth of palliative care teams, clinicians may rightfully question which palliative care skills should simply be part of "good medical care." Many of the skills used by palliative care clinicians are indeed aspects of high-quality care that should be provided by a patient's primary care clinician or primary specialty caregiver (eg, pulmonologist or cardiologist). While training in these areas has traditionally been neglected in medical education, the increasing numbers of patients facing a serious illness require that all providers develop basic competency in symptom assessment and initial management along with basic discussions about goals of treatment and prognosis.¹ Sub-specialty level palliative care is needed when treating complex pain and nonpain symptoms, managing complex and/or highly conflict-rich communication interactions with patients and families, and responding to complicated, multifaceted psychosocial and/or spiritual distress. Such challenging clinical tasks require specialty training along with dedicated time and space to focus on such concerns. The Table provides examples of reasons to refer patients for palliative care consultation and collaboration.

TABLE. Putting It All Together: Practical Reasons to Call Palliative Care Specialists

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|--|
| <p>Assistance with complex symptom management</p> <ul style="list-style-type: none"> • Managing escalating or refractory symptoms (eg, pain, dyspnea, and nausea) • Complex pharmacologic management in patients facing a life-limiting illness (eg, opioid infusions, opioid rotations, patient-controlled analgesia, methadone initiation, and ketamine initiation) • Addressing complex depression, anxiety, grief, and existential, spiritual, or psychosocial distress • Respite and/or palliative sedation for intractable symptoms |
| <p>Care of complex, severely ill patients over time</p> <ul style="list-style-type: none"> • New diagnosis with metastatic cancer and/or malignancy with high symptom burden • Frequent hospital admissions for the same diagnosis of a serious illness • Intensive care unit admission with metastatic cancer • Intensive care unit admission with poor prognosis • Prolonged intensive care unit stay |
| <p>Assistance with medical decision making and determining goals of care</p> <ul style="list-style-type: none"> • Discussing transitions in care • Complex and/or evolving goals of care discussions • Assistance with conflict resolution regarding goals or methods of treatment, whether that conflict is within the family, between the family and the medical teams, or between treatment teams • Redefining hope, in the setting of complex illness • Complex code status discussions • Assistance with managing patient and/or family conflict or complex social issues • Ethical dilemmas |
| <p>Questions regarding future planning needs</p> <ul style="list-style-type: none"> • Determining and discussing prognosis, where desired • Care and planning in the setting of advanced illness <ul style="list-style-type: none"> • Consider referral when one would answer "yes" to the question, "Would I be surprised if my patient died within 12 months?" • Discussing issues pertaining to artificial feeding or hydration • Determining present and future care needs • Help with determining hospice eligibility and providing hospice education |

10. PALLIATIVE CARE ENHANCES HEALTH CARE VALUE

How does palliative care fit into a health care system in which attention has shifted to improving quality of a care without also increasing cost? Interestingly, increasing health care expenditures have not been associated with better care at the end of life, when patients and families may continue to experience untreated symptoms, caregiver distress, and poor quality of life.^{7,47} Conversely, analysis of more than 5000 patients suggests that palliative care involvement has been associated with a cost savings of \$1696 per admission for patients who survived hospitalization and \$4908 per admission for patients who did not survive hospitalization. Palliative care

involvement was associated with significant reductions in pharmacy, laboratory, and intensive care costs.⁴⁸ Other studies have found a cost benefit with palliative care involvement associated with reductions in intensive care unit length of stay and a variety of other cost-avoidance mechanisms.⁴⁹⁻⁵¹

Notably, cost improvement associated with palliative care involvement has not come at the expense of quality of care. In fact, the opposite seems to be true. Palliative care is associated with improvement in quality of life,⁵ mood,⁵ and patient and family satisfaction.⁵² Hence, given that 90 million Americans currently live with a serious and life-threatening illness, a number that is only likely to increase, palliative care will play an integral role in a changing health care landscape that is increasingly focused on providing higher-quality care at a lower cost.

The Table provides some examples of common reasons to seek palliative care consultation. In addition, the Center to Advance Palliative Care website (www.getpalliativecare.org) provides information for clinicians, patients, and caregivers to learn more about palliative care and its role in helping patients with a serious or life-threatening illness.

CONCLUSION

Palliative care is a multidisciplinary specialty focused on improving the quality of life of patients with serious illness and their families. Its model of care is centered on reducing symptom burden, attending to psychosocial needs, and working with patients, families, and clinicians to align care with a patient's goals. Rather than merely end-of-life care, palliative care teams are available to help clinicians care for patients and their families at any age and any stage of a serious illness, including those who are actively undergoing disease-targeted therapies. Notably, palliative care seems to yield greater benefit for patients and their families when involved early in a disease course. This involvement leads to more effective and efficient care associated with cost savings, not less care.

Abbreviations and Acronyms: CHF = congestive heart failure; COPD = chronic obstructive pulmonary disease

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