

Palliative Care and the Quality of Life

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Catherine is a 27-year-old woman who was waitressing to save money for graduate school. She had no insurance and was hoping that her fatigue and nosebleeds were attributable to stress and dry air in her city apartment. Her roommate found her collapsed on the floor and called 911. A complete blood count in the emergency department revealed 50,000 blasts in the periphery, and Catherine was diagnosed with leukemia. Symptoms included severe bone pain, dyspnea, anxiety, and panic attacks associated with isolation. Catherine's brother had a history of substance abuse, and her parents were opposed to using opioids for her pain. House staff prescribed acetaminophen with codeine every 6 hours as needed without benefit. Catherine would cry out in pain and kept pushing the call bell for relief, but the nurses told her she must wait until 6 hours were up. The palliative medicine consult team was called for "help with a manipulative, drug-seeking patient." After changes in her opioid regimen, Catherine's symptoms and psychological distress were markedly improved. Both she and her family required extensive counseling and support not only about the harms of untreated pain and the safe use of opioids but also about the existential, spiritual, economic, and emotional consequences of Catherine's illness. The palliative care team worked side by side with the hematologists through Catherine's bone marrow transplant. Six years later, she had finished graduate school and married. She and her family send an annual holiday card and contribution thanking the hospital for the expert scientific and compassionate care they received.

Catherine's story exemplifies the benefits of palliative care and oncology comanagement. The goal of her oncology care was cure, yet her palliative care needs posed significant—but remediable—burdens on the patient, her family, and the medical care team. Despite the logic of a simultaneous palliative and disease management approach for patients with cancer, the medical profession persists in thinking about palliative care as being synonymous with end-of-life care or as being what we do when there is nothing more that we can do. Medical care is falsely but widely understood to have two mutually exclusive goals: to cure disease and prolong life or to provide comfort care. Consequently, the decision to focus on the reduction of suffering is typically made only after life-prolonging treatment becomes ineffective or too burdensome and death is imminent. This problem was recognized in February 2011 by important new American Society of Clinical Oncology guidelines¹ that call for proactive discussions and quality-of-life-focused care for all patients with cancer, not only those with advanced or end-stage disease.

The confusion about similarities and differences between palliative care and hospice (end-of-life) care is understandable. Philosophically, palliative care is a broad construct defining a continuum that

serves patients and families from the time of diagnosis with a chronic or acute progressive illness throughout the entire course of the disease. Hospice and palliative care professionals have expertise in symptom management and in the communication skills necessary to facilitate discussions with patients and families about treatment options, preferences, and goals of care. Although the similarities between palliative care and hospice are important, it is the differences between them that enable realization of the full value of this approach to caring for patients. Specifically, hospice professionals focus on caring for patients with a clearly limited life expectancy and who have made an informed decision to discontinue curative care. Volunteers and bereavement services are important components of the comprehensive hospice model. Hospice care can be provided in any setting, and the large majority of patients receive hospice care in their own homes.²

In contrast, palliative care practitioners working outside of hospice programs provide their expertise to patients who wish to and continue to benefit from curative and life-prolonging therapies. As a formally recognized³⁻⁵ new medical subspecialty, palliative medicine practitioners work in collaboration with other specialists to care for patients with serious or advanced illness. At present, most palliative care services outside of hospice are provided in the hospital setting and emphasize expert symptom management and matching treatments to informed and achievable patient and family goals. Palliative care teams also offer practical support and mobilization of community resources to ensure a sustainable and safe living environment after discharge from the hospital and support continuity across a range of care settings (ie, hospital, home, nursing home, and hospice).²

Along with the scientific progress that has successfully converted many rapidly fatal cancers to chronic diseases with which patients may now live for years, the need for palliative care is no longer linked to prognosis. Instead, palliative care should be provided to all patients with serious or advanced illness, independent of prognosis or receipt of disease-specific treatment. Research demonstrates that palliative care improves symptom distress, quality of life, patient and family well-being, and in some settings (eg, advanced lung cancer), survival. Palliative care also reduces the unnecessary use of hospitals, diagnostic and treatment interventions, and nonbeneficial intensive care.⁶⁻¹¹

Adverse consequences of our adherence to the traditional either/or model of curative and comfort care are significant. Patients with cancer and their families report pain and other symptoms¹²; inadequate time with their doctors¹³⁻¹⁵; and misunderstanding of the nature of their illness and the benefits and burdens of treatments.¹⁵ Paramount fears of uncontrolled physical symptoms such as pain and breathlessness¹⁶ are often justified. A recent systematic review of 52

studies^{17,18} found a pain prevalence of 33% among survivors of cancer, 59% in those undergoing active treatments, 64% among patients with advanced or metastatic disease, and 53% averaged across all disease stages. One third of those reporting pain rated it as moderate or severe. Aside from patient misery, pain is associated with several adverse outcomes including depression (an independent predictor of shortened survival),^{19,20} other mood disorders,^{21,22} delirium,²³ functional decline,²⁴ and the development of chronic pain syndromes. Nonpain physical symptoms (eg, breathlessness), depression, anxiety, and other psychological symptoms (eg, delirium) are also commonly under-assessed and undertreated in the setting of cancer.^{17,25,26}

The accumulating evidence of the harmful effects of pain and symptom distress and the benefits of palliative care in addressing them argue for earlier and greater involvement of palliative care in the treatment of cancer. The mechanism of these benefits is unknown, but studies suggest that prolonged stressors associated with serious illness diminish immune reserve and that psychosocial, symptom, and other quality-of-life interventions provided by palliative care might disrupt this pathway and lead to improved outcomes. A relationship between psychologic and physical stressors and lowered host resistance may also explain recent findings of increased mortality in stressed caregivers of patients with cancer (up to 60% in one study)^{27,28} and the five- to nine-fold increase in risk of post-traumatic stress and prolonged grief disorders^{10,29} in family caregivers of patients with cancer who died in a hospital or an intensive care unit.

Physicians are data driven. We strive to synthesize and mobilize the best of modern medical science on behalf of our patients. Pain and symptom distress, mood disorders, and family caregiver burden are prevalent and carry significant adverse consequences for our patients and their families. Medical care focused on addressing these burdens—pain and other symptoms, mood disorders, and matching care to honestly informed and achievable goals—not only improve quality of life and reduce depression but, as recent studies suggest, may also improve survival.^{6,7,20,30-32} In addition, such interventions pose low or no risk and, compared with other cancer treatments, are low in cost. In light of these data, why is the belief that palliative care only becomes appropriate when it is obvious that the patient is dying so persistent?

Reasons advanced to account for resistance to palliative care comanagement include modern medicine's singular focus on disease-specific treatment, confusion about the different but complementary roles of palliative care and hospice, and inadequate exposure to simultaneous deployment of best cancer care with palliative approaches from the time of diagnosis during medical training. Finally, oncologists may fear that comanagement with palliative care specialists may be experienced by patients as a form of abandonment, particularly if chemotherapy is no longer warranted. This possibility is supported by recent studies demonstrating oncologist preference for the term "supportive" rather than "palliative" care.^{33,34}

Improving recognition of the value of palliative care from diagnosis of a serious cancer requires palliative medicine competency requirements for oncology trainees as well as system redesigns that routinize provision of primary- and, when needed, specialty-level palliative care in standard cancer care protocols and delivery models. In recognition of this quality gap, the major professional and consumer advocacy cancer organizations have been unanimous in recent years in their recognition of the importance of concurrent palliative care regardless of prognosis and of whether the goal of care is cure (as in Catherine's story), life prolongation, or solely comfort.^{1,5,35,36} Ma-

major certifying bodies such as the American College of Surgeons' Commission on Cancer³⁷ require access to palliative care from diagnosis as a condition of certification. Variable availability of outpatient services is a major barrier to early access to palliative care; investment in the necessary staff, resources, and space will be required if cancer centers are to adhere to these new standards.³⁸ Similarly, the growing number of outpatient survivorship programs provide palliative care focused both on the long-term effects of cancer and its treatment and on ongoing oncologic surveillance.³⁹

New delivery and payment models that promote quality of care (instead of the current fee-for-service model that promotes quantity of care) may change incentives that encourage procedures and interventions over whole-person care. Our patients will benefit, and so will we, because professional satisfaction lies in the genuine human connection that we are privileged to share with the patients we serve. Caring for the modern patient with cancer requires palliative care at the same time as cancer-focused treatments. Francis Peabody said it best in 1927: "the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient."⁴⁰

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