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-

yor 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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REFERENCES

1. Peppercorn JM, Smith TJ, Helft PR, et al: American Society of Clinical Oncology statement: Toward individualized care for patients with advanced cancer. *J Clin Oncol* 29:755-760, 2011
2. Morrison RS, Meier DE: Clinical practice: Palliative care. *N Engl J Med* 350:2582-2590, 2004
3. American Board of Hospice and Palliative Medicine: ABMS votes to make Hospice and Palliative Medicine an ABMS subspecialty. <http://www.aahpm.org/certification/default/abms.html>
4. Scharfenberger J, Furman CD, Rotella J, et al: Meeting American Council of Graduate Medical Education guidelines for a palliative medicine fellowship through diverse community partnerships. *J Palliat Med* 11:428-430, 2008
5. Ferris FD, Bruera E, Cherny N, et al: Palliative cancer care a decade later: Accomplishments, the need, next steps—From the American Society of Clinical Oncology. *J Clin Oncol* 27:3052-3058, 2009
6. Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
7. Bakitas M, Lyons KD, Hegel MT, et al: Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA* 302:741-749, 2009
8. Morrison RS, Penrod JD, Cassel JB, et al: Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med* 168:1783-1790, 2008
9. Siu AL, Spragens LH, Inouye SK, et al: The ironic business case for chronic care in the acute care setting. *Health Aff (Millwood)* 28:113-125, 2009
10. Wright AA, Keating NL, Balboni TA, et al: Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 28:4457-4464, 2010
11. Wright AA, Zhang B, Ray A, et al: Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300:1665-1673, 2008
12. Desbiens NA, Mueller-Rizner N, Connors AF, Jr., et al: The symptom burden of seriously ill hospitalized patients: SUPPORT investigators—Study to Understand Prognoses and Preferences for Outcome and Risks of Treatment. *J Pain Symptom Manage* 17:248-255, 1999
13. Teno JM, Clarridge BR, Casey V, et al: Family perspectives on end-of-life care at the last place of care. *JAMA* 291:88-93, 2004

14. Shield RR, Wetle T, Teno J, et al: Physicians "missing in action": family perspectives on physician and staffing problems in end-of-life care in the nursing home. *J Am Geriatr Soc* 53:1651-1657, 2005
15. Huskamp HA, Keating NL, Malin JL, et al: Discussions with physicians about hospice among patients with metastatic lung cancer. *Arch Intern Med* 169:954-962, 2009
16. Singer PA, Martin DK, Kelner M: Quality end-of-life care: Patients' perspectives. *JAMA* 281:163-168, 1999
17. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, et al: Quality of life and non-pain symptoms in patients with cancer. *J Pain Symptom Manage* 38:216-233, 2009
18. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, et al: Prevalence of pain in patients with cancer: A systematic review of the past 40 years. *Ann Oncol* 18:1437-1449, 2007
19. Satin JR, Linden W, Phillips MJ: Depression as a predictor of disease progression and mortality in cancer patients: A meta-analysis. *Cancer* 115:5349-5361, 2009
20. Giese-Davis J, Collie K, Rancourt KM, et al: Decrease in depression symptoms is associated with longer survival in patients with metastatic breast cancer: A secondary analysis. *J Clin Oncol* 29:413-420, 2011
21. Chang VT, Thaler HT, Polyak TA, et al: Quality of life and survival: The role of multidimensional symptom assessment. *Cancer* 83:173-179, 1998
22. Portenoy RK, Itri LM: Cancer-related fatigue: Guidelines for evaluation and management. *Oncologist* 4:1-10, 1999
23. Morrison RS, Magaziner J, Gilbert M, et al: Relationship between pain and opioid analgesics on the development of delirium following hip fracture. *J Gerontol A Biol Sci Med Sci* 58:76-81, 2003
24. Morrison RS, Flanagan S, Fischberg D, et al: A novel interdisciplinary analgesic program reduces pain and improves function in older adults after orthopedic surgery. *J Am Geriatr Soc* 57:1-10, 2009
25. Spiegel D: Mind matters in cancer survival. *JAMA* 305:502-503, 2011
26. Mitchell AJ, Chan M, Bhatti H, et al: Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: A meta-analysis of 94 interview-based studies. *Lancet Oncol* 12:160-174, 2011
27. Schulz R, Newsom J, Mittelmark M, et al: Health effects of caregiving: The caregiver health effects study: An ancillary study of the Cardiovascular Health Study. *Ann Behav Med* 19:110-116, 1997
28. Schulz R, Beach SR: Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA* 282:2215-2219, 1999
29. Siegel MD, Hayes E, Vanderwerker LC, et al: Psychiatric illness in the next of kin of patients who die in the intensive care unit. *Crit Care Med* 36:1722-1728, 2008
30. Connor SR, Pyenson B, Fitch K, et al: Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *J Pain Symptom Manage* 33:238-246, 2007
31. Thornton LM, Andersen BL, Schuler TA, et al: A psychological intervention reduces inflammatory markers by alleviating depressive symptoms: Secondary analysis of a randomized controlled trial. *Psychosom Med* 71:715-724, 2009
32. Andersen BL, Yang HC, Farrar WB, et al: Psychologic intervention improves survival for breast cancer patients: A randomized clinical trial. *Cancer* 113:3450-3458, 2008
33. Dalal S, Palla S, Hui D, et al: Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *Oncologist* 16:105-111, 2011
34. Fadul N, Elsayem A, Palmer JL, et al: Supportive versus palliative care: What's in a name?—A survey of medical oncologists and midlevel providers at a comprehensive cancer center. *Cancer* 115:2013-2021, 2009
35. National Coalition for Cancer Survivorship: Cancer Advocacy Priorities, 2009. <http://www.canceradvocacy.org/take-action/nccs-policy/policy-priorities.html>
36. American Cancer Society: Improving patients' quality of life through palliative care. <http://www.cancer.org/Cancer/news/Features/improving-patients-quality-of-life-through-palliative-care>
37. American College of Surgeons Commission on Cancer: Working draft: Cancer program standards 2012—Ensuring patient-centered care. <http://www.facs.org/cancer/coc/cps2012draft.pdf>
38. Hui D, Elsayem A, De la Cruz M, et al: Availability and integration of palliative care at US cancer centers. *JAMA* 303:1054-1061, 2010
39. Ganz PA: Quality of care and cancer survivorship: The challenge of implementing the institute of medicine recommendations. *J Oncol Pract* 5:101-105, 2009
40. Peabody F: The care of the patient. *JAMA* 88:877-882, 1927

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