Palliative Care

Time for Better Integration of Oncology and Palliative Care

By Amy P. Abernethy, MD, and David C. Currow, BMed, MPH, FRACP

Duke University Medical Center, Durham, NC; Flinders University, Bedford Park, South Australia, Australia

We are honored to be a part of this edition of *Journal of Oncology Practice* focused on palliative care. Many thoughtful authors have contributed their insights and research observations to bring you a snapshot of modern palliative care and how it intersects with oncology.

Palliative care is an active and systematic approach to addressing issues that are important to patients and families in the setting of serious illness, and is aimed at yielding improvements in quality of life and relief of suffering. It is focused on optimizing people's function and comfort in the shadow of a limited life expectancy in all of the domains that make us who we are: physical, emotional, spiritual, sexual, social and financial. Most simply stated, palliative care is about living life to the full when faced with the reality of life-threatening illness. Such a focus requires specific conversations, and must be part of an ongoing and carefully recorded conversation about a gravely ill patient's preferences (and their values underpinning those preferences) for care in the context of their life, as described by Ahluwalia et al¹. Palliative care can (and should) be delivered simultaneously with antineoplastic treatment whenever the aim of that therapy is not explicitly curative, or it can be delivered as the sole focus of care; ideally, oncologists and palliative care clinicians should work together on a day-to-day basis.

Palliative care also encompasses caregivers and other loved ones, many of whom have significant health and emotional needs that are mostly not addressed. Caregivers have a dual relationship with health and social services¹: they are fellow workers in providing care, and they are care recipients as they are supported through one of life's most harrowing experiences, the dying and death of someone they love.

A diagnosis of cancer is still associated strongly with imminent mortality. If you do nothing else, we recommend the essay that Susan Stone wrote before her stem-cell transplant for cancer.² In the face of death, life becomes all the more important, pressing, and present. How can each of us in clinical practice help people to realize their goals and dreams as they face cancer? How can we at the same time help to maintain the normality of everyday life?

There is a coalescence of trends: the aging of the population, greater burden of chronic illness, increasing multimorbidity among people with advanced cancer (see Ritchie et al³), rising health care expenditures (partly due to overtreatment), and accumulating evidence on the benefits of palliative care in optimizing patient outcomes. Recognition of unmet symptom management needs across the disease trajectory is motivating

the incorporation of palliative care earlier in the disease care process and, ideally, as a supportive option throughout the full continuum of care. A recent randomized control trial published in the *New England Journal of Medicine* by Temel et al⁴ suggested that early application of palliative care improved life expectancy by more than 2 months (a magnitude of benefit that has seen many expensive targeted therapies licensed for use), improved quality of care, and reduced costs for people with metastatic lung cancer. This high-profile study heightened awareness that the health care delivery system should make palliative care available to address the needs of patients who are suffering from serious life limiting illness before their last few days of life, in order to improve overall survival and quality of life, as well as health care utilization. It is complemented by work demonstrating the health and survival benefits to caregivers long after they have relinquished their role.^{5,6}

In response, palliative care is rapidly evolving, growing, and increasing in visibility. There is an expanding evidence base that underpins its contribution to health and well-being, as well as the evidence supporting the individual interventions used by palliative care providers. There has been stepwise professionalization of practice; the American Board of Medical Specialties and Accreditation Council for Graduate Medical Education formally recognized palliative medicine as a medical subspecialty in the United States in 2006. In his article, DeBono⁷ reviews the progressive integration of palliative care into routine cancer care. Epstein et al⁸ describe the evolving policy landscape and innovative solutions to support advance care planning. In the light of the evolving evidence base, they describe the imperative to ensure that the models of care (and reimbursement to facilitate such changes) accommodate new knowledge as it comes to light.

Models for palliative care delivery are inherently diverse. Patients receiving palliative care comprise a highly heterogeneous population, spanning diseases, ages, and most other categorical divides. They receive care in various settings, ranging from hospital-based palliative care units to outpatient clinics, freestanding hospices, nursing facilities, and the home. Palliative care is inherently interdisciplinary, involving physicians, nurses, social workers, physical and occupational therapists, pharmacists, counselors, chaplains and other clergy, and individuals such as music therapists and complementary therapy providers. Care is planned and delivered in a team context; the approach coordinates the contributions of various care providers to optimize the well-being of the patient as a whole person in

the context of the people who support the patient: family and friends.

At present, the dominant model of palliative care service provision in the United States is hospice. Hospice provides intensive palliative services delivered by a multidisciplinary team to persons who are believed to have less than 6 months to live (although access to this in the United States is generally < 1 month before death).⁹ The creation of the Medicare hospice benefit in the early 1980s led to the establishment of structured clinical services to care for people at the end of life, and provided a financing model that transformed grassroots efforts into a viable model of health care delivery. Hospice is important, but when it is the only available model then we miss the opportunity to intervene earlier in the course of illness, when best quality of life can be both realized and enjoyed. This needs to happen alongside cancer care. In the Temel study, we see a glimpse into the next extension of what palliative care could be, and arguably should be, for patients with cancer, in the clinic and in the community.⁴ We must augment the currently reimbursed model, hospice, with what patients need—palliative care available in all of the venues of care—home, hospital, nursing home, and clinic.

So how do we make that happen? In the United States, the next step has been the development of inpatient palliative care consultative services. As of 2009, more than 60% of hospitals had consultative services (see www.capc.org), and the number continues to rapidly increase. Palliative care services may or may not have their own inpatient beds. Freestanding or inpatient hospice beds are also available.

But there is still a gap: the community. As Kamal et al^{10(pxxx)} describe: “Most [people needing palliative care] are living and receiving care ‘in the community,’ that is, in their personal homes or other private homes, nursing homes, and retirement communities. Thus they confront the psychological, social, emotional, and spiritual issues related to advanced cancer, as well as burdensome cancer-related symptoms, in a context often far removed from a cancer center.” New delivery models are emerging, as described by Debono and Kamal et al.^{8,10} Examples include palliative care clinics, in the oncologists office or elsewhere, as well as “bridging” palliative care services, intended to ensure continuity of care and facilitate the patient’s transition from aggressive therapy to hospice care, with acute and curative care occurring simultaneously and jointly. Late in the illness trajectory (generally the last days to weeks), hospice is still appropriately the predominant care model. In other resource-rich countries, all of these models of care often coexist and are seamlessly available; this model is occasionally described as specialized palliative care services.⁵ Given the needs of the population, there has to be a trained workforce not only to provide care, but to educate the next generation of health professionals and to continue to refine the evidence base that informs best practice. Until reimbursement and workforce issues are resolved in the United States, development of community-based models will be slow.

How do we ensure that palliative interventions are making the intended impact? How do we identify people most likely to

benefit and ensure timely referral? In palliative care, the patient’s experience is paramount. In fact, the impact and effectiveness of palliative care is judged independently of traditional outcomes such as death or cure. Caregiver outcomes, such as reduced psychological distress and fatigue, are important targets of monitoring and intervention in palliative care. Assessment, quality improvement, and timely referral can happen only through systematic monitoring using routine data collection, supplemented by specific audits that highlight unmet needs that can be addressed through timely involvement of palliative and hospice care. Glare et al¹¹ describe an approach to identify people with palliative care needs within oncology clinics by using referral criteria and systematic evaluation of clinic notes. The authors highlight that this process is resource intense, and that newer methods are needed. Suh et al¹² report a system in which patients report symptoms, psychosocial concerns, and changes in physical functioning at each cancer clinic visit using tablet computers. They demonstrate how routine patient-reported data collection can function as a review of systems and generate patient-reported assessments of performance status that may be as predictive of survival as physician-reported performance status, especially when the trajectory is monitored over time. Perhaps these methods will provide an efficient, practical strategy to identify patients with cancer who need palliative care. Performance status is a linking language between oncology and palliative care, and as LeBlanc and Back describe, “by better tracking and responding to changes in patients’ performance status, we can make more precise interventions earlier in the course of a patient’s decline.”^{13(pxxx)}

And finally, palliative care is also about recognizing that people do die. Hoverman¹⁴ reminds us that at the end of the day, our job is to support people, especially if they are dying. This care is both physical and metaphysical. Sometimes it truly is not practical to provide adequate care in the place where a person wants to die, but we can provide the emotional and spiritual care that people require wherever they are. In order to better match where people die with where they want to die, we first need to ask. We need to learn to have the difficult conversations and know practically how to respond.⁹ So often we are afraid of such conversations because, as clinicians, we feel the need to have all the answers. Patients and their families do not expect all the answers, simply the courage to broach the topics.³ We need to partner with care providers of all backgrounds who can help make it possible—hospice, palliative care, home health, family, and friends—in brokering the hardest conversations and most complex care that we face professionally.

Stated this way, the need to increase the use of palliative care seems too obvious. But, when we put out this call for papers on palliative care for *Journal of Oncology Practice* the first group of manuscripts we received could be generally categorized as being concerned with “end-of-life (or terminal) care.” End-of-life care—in the last days to weeks of life—is a critical subset of palliative care, but it is only part of the story. If this is the sole focus, patients, families, clinicians, and the health care system miss specific opportunities to provide better care. For this reason, we carefully supplemented the submitted work about end-

of-life care with important manuscripts about issues of emerging importance to palliative care in oncology. As more people in our communities experience an “expected” death from cancer or chronic, progressive end-stage system failure, palliative care provides a structured, rational, patient-centered approach to the provision of high-quality, cost-effective care that better meets the needs of patients, their families, and caregivers. As palliative care is increasingly woven into the fabric of health care, it will be critical to see that it is mainstreamed into the cancer care enterprise. The rewards to be gained will be manifest, and will help redirect patient care back to its roots in relieving suffering and focusing on living.

Accepted for publication on October 3, 2011.

Authors' Disclosures of Potential Conflicts of Interest

Although all authors completed the disclosure declaration, the following author(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a “U” are those for which no compensation was received; those relationships marked with a “C” were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

References

1. Ahluwalia SC, Chuang FL, Antonio ALM, et al: Documentation and discussion of preferences for care among patients with advanced cancer. *J Oncol Pract* 7:361-366, 2011
2. Stone S: Perspectives from the other side: A physician and cancer survivor. *J Oncol Pract* 7:348-350, 2011
3. Ritchie CS, Kvale E, Fisch M: Multimorbidity: An issue of growing importance for oncologists. *J Oncol Pract* 7:371-374, 2011
4. 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
5. Abernethy AP, Currow DC, Fazekas BS, et al: Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. *Support Care Cancer* 16:585-597, 2008
6. Christakis NA, Iwashyna TJ: The health impact on families of health care: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Soc Sci Med* 57:465-475, 2003
7. Debono DJ: The integration of palliative medicine into routine oncological care: What does the evidence show us? *J Oncol Pract* 7:350-354, 2011

Employment or Leadership Position: None **Consultant or Advisory Role:** Amy P. Abernethy, Helsinn Therapeutics (C), Amgen (C), Novartis (C) **Stock Ownership:** None **Honoraria:** None **Research Funding:** Amy P. Abernethy, Pfizer, Eli Lilly, Mi-Co, Bristol Meyers Squibb, Helsinn Therapeutics, Amgen, Kanglaite, Alexion, Biovex, DARA Therapeutics, Novartis **Expert Testimony:** None **Other Remuneration:** None

Author Contributions

Conception and design: David C. Currow

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Amy P. Abernethy, MD, Duke University Medical Center, Box 3436, Durham, NC 27710; e-mail: amy.abernethy@duke.edu.

Amy P. Abernethy is Associate Professor of Medicine, Division of Medical Oncology, Duke University Medical Center, Durham, NC. David C. Currow is Professor, Department of Palliative and Supportive Services, Division of Medicine, Flinders University, Bedford Park, South Australia, Australia.

DOI: 10.1200/JOP.2011.000467

8. Epstein AS, Volandes AE, O'Reilly EM: Building on individual, state and federal initiatives for advance care planning, an integral component of palliative and end-of-life cancer care. *J Oncol Pract* 7:355-359, 2011
9. Christakis NA, Escarce JJ: Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med* 335:172-178, 1996
10. Kamal AH, Bull J, Kavalieratos D, et al: Palliative care needs of patients with cancer living in the community. *J Oncol Pract* 7:382-388, 2011
11. Glare P, Semple D, Stabler S, et al: Palliative care in the outpatient oncology setting: Evaluation of a practical set of referral criteria. *J Oncol Pract* 7:366-380, 2011
12. Suh SY, LeBlanc TW, Shelby RA, et al: Longitudinal patient-reported performance status assessment in the cancer clinic is feasible and prognostic. *J Oncol Pract* 7:374-380, 2011
13. LeBlanc TW, Back AL: Linking palliative care and oncology practice: Performance status as a common thread. *J Oncol Pract* 7:381-382, 2011
14. Hoverman JR: Taking care: Community, family, and dying in place. *J Oncol Pract* 7:359-361, 2011

Perspectives From the Other Side: A Physician and Cancer Survivor

By Susan C. Stone, MD, MPH

Cedars Sinai Medical Center, Los Angeles, CA

Introduction

Living with an unpredictable and progressive illness challenges the strongest of humans. Cancer is the ultimate life changer and leaves a significant impact on both the individual and caregivers. Those undergoing treatment will have burdensome symptoms and pain,

psychological and existential distress, which can often go under-treated. ASCO has made great strides to integrate palliative care into the comprehensive care model. However, much work remains to ensure that all patients, whether receiving curative or palliative therapy, have a good quality of life.