19. Yellen SB, Cella DF, Webster K, et al: Measuring fatigue and other anemia-related symptoms with the Functional Assessment of Cancer Therapy (FACT) measurement system. *J Pain Symptom Manage* 13:63-74, 1997

20. Webster, K, Cella D, Yost K: The Functional Assessment of Chronic Illness Therapy (FACIT) measurement system: Properties, applications, and interpretation. *Health Qual Life Outcomes* 1:79, 2003

21. Cella DF, Bonomi AE, Lloyd SR, et al: Reliability and validity of the Functional Assessment of Cancer Therapy-Lung (FACT-L) quality of life instrument. *Lung Cancer* 12:199-220, 1995

22. Houts, AC, Fortner BV, Schwartzberg L: The Patient Care Monitor (PCM) manual and psychometric information for PCM 1.0, PCM 1.0 Revised, and PCM 2.0. Germantown, TN, Supportive Oncology Services, 2007

23. Brucker PS, Yost K, Cashy J, et al: General population and cancer patient norms for the Functional Assessment of Cancer Therapy-General (FACT-G). *Eval Health Prof* 28:192-211, 2005

24. Santana MJ, Au HJ, Dharma-Wardene M, et al: Health-related quality of life measures in routine clinical care: Can FACT-fatigue help to assess the management of fatigue in cancer patients? *Int J Technol Assess Health Care* 25:90-96, 2009

Linking Palliative Care and Oncology Practice: Performance Status As a Common Thread

By Thomas W. LeBlanc, MD, MA, and Anthony L. Back, MD

Duke University Medical Center, Durham, NC; University of Washington; Fred Hutchinson Cancer Research Center, Seattle, WA

Introduction

Aspirations to integrate palliative medicine into comprehensive cancer care are hardly novel. In a 1998 position statement from ASCO, authors describe “the oncologists’ responsibility to care for their patients in a continuum that extends from the moment of diagnosis throughout the course of the illness . . . include[ing] symptom control and psychosocial support during all phases of care.”¹ It is also clear, as shown by public opinion polling, that a majority of patients want access to palliative care services in the setting of serious illness.² More than a decade later, however, ASCO’s vision statement for 2020 recognizes that we still have a long way to go in realizing this objective.³ Why has it been so difficult to integrate these two specialties?

Perhaps this struggle is an operational one, stemming from difficulty in conceptualizing what this integration might actually look like in the clinic. For example, one might wonder, for a patient receiving aggressive chemotherapy, what should trigger a referral to a palliative care specialist? ASCO’s vision for 2020 recognizes that today’s model of cancer care should no longer be one of “cure versus comfort,” yet it can still often feel this way in clinical practice, as we move through each successive standard line of therapy until no options remain.³ Under this older model, palliative care referrals occur very late, when patients either have no remaining therapeutic options or become too debilitated to benefit from or tolerate further chemotherapy.

Performance status, a common concept in both oncology and palliative care practice, may be just the sort of trigger we need to fix this problem, by enabling earlier and more targeted referrals to palliative care specialists. 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. Consider the following case:

Mrs F is a 67-year-old woman with stage IV non–small-cell lung cancer. She lives independently and drives herself to all appointments. Her treatment regimen has included multiple courses of standard therapies, such that she is now being treated with single-agent vinorelbine. Recent scans show stable disease, but today she arrives to clinic in a

wheelchair, with her daughter, who reveals that her mom has been struggling with activities of daily living for the last few months, and even fell several times this week while trying to cook meals and clean the house. On further questioning, she has suffered progressive functional decline over the last 3 to 4 months, which was not evident to her doctors as she still drove herself to the clinic.

This scenario is not an uncommon one. Patients often seem to suddenly fall off the proverbial performance status cliff one day in clinic, and it does not always correlate with objectively measurable disease. When a patient like Mrs F arrives in a wheelchair for the first time, red flags go up, often triggering difficult discussions and decision making about how to proceed. One wonders, is palliative chemotherapy providing further benefit in the setting of worsened performance status? Were there earlier signs of her functional decline? Could we have detected this sooner, and intervened then to prevent her falls? Is it time for hospice? Yet when we talk with patients or family members further, we may find—as in this case—that there were subtle changes over the preceding weeks to months that could have altered our approach. Typical measures of performance status are not sensitive enough to detect these changes, are not performed frequently enough, and are not trended over time. We thus miss out on opportunities to recognize these important changes earlier, and to intervene.

Patient-reported performance status assessment, as described by Suh et al⁴ in this issue of *JOP*, could fundamentally change this aspect of our practice. By using electronic methods for collecting, analyzing, and organizing how patients report their own performance status, we can turn a parameter that was unused and inaccessible into a valid piece of data that clinicians and patients could learn from, and even use to inform targeted interventions. As Suh et al suggest, changes in performance status over time likely have predictive power in terms of patients’ survival. Current usage of performance status assessment, on the other hand, barely scratches the surface of what it can and should be doing for us in clinical practice. Most modern medical record systems do not provide a searchable field to document performance status measures, thereby also precluding higher level usage thereof, such as trending values over time in order to visualize patients’ trajectories.

Armed with these new, robust data points, we can better meet patients' goals. Appropriate use of aggressive therapies can enhance patients' quality of life, improve symptoms, and increase longevity. Without a better early warning system, however, we will continue to fall short of meeting these expectations near the end of life, when aggressive therapies may no longer yield benefit, and perhaps even pose harm. Patient-reported performance status assessments stand poised to take us one step closer to meeting this goal, which could also even result in cost-savings for the healthcare system. Adoption of this approach could be a needed step forward, toward more seamless integration of palliative care practice into comprehensive cancer care, in accordance with ASCO's stated vision for 2020.³

Accepted for publication on September 21, 2011.

References

1. Cancer care during the last phase of life. *J Clin Oncol* 16: 1986-1996, 1998
2. Center to Advance Palliative Care: Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies. <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>
3. 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
4. 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* 7:374-381, 2011

Palliative Care Needs of Patients With Cancer Living in the Community

By Arif H. Kamal, MD, Janet Bull, MD, Dio Kavalieratos, BPhil, Donald H. Taylor Jr, PhD, William Downey, MSW, and Amy P. Abernethy, MD

Division of Medical Oncology, Department of Medicine; Duke Cancer Care Research Program, Duke Cancer Institute, Duke University Medical Center; Sanford Institute of Public Policy, Duke University, Durham; Four Seasons, Flat Rock; Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC

Abstract

Purpose: With improved effectiveness of early detection and treatment, many patients with cancer are now living with advanced disease and associated symptoms. As cancer becomes a chronic illness, adequate attention to patients' symptoms and psychosocial needs in the community setting requires positioning of palliative care alongside cancer care. This article describes the current palliative care needs of a population of community-dwelling patients with advanced cancer who are not yet ready for transition to hospice.

Methods: This secondary analysis used quality-monitoring data collected in three community-based palliative care organizations. Analyses focused on people with cancer-related diagnoses who were receiving palliative care during 2008 to 2011.

Results: The analytic data set included 4,980 people, 10% of whom had cancer. Median age was 71 years. Forty-eight percent

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

Author Contributions

Conception and design: Thomas W. LeBlanc, Anthony L. Back

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Thomas W. LeBlanc, MD, MA, Box 3841, Duke University Medical Center, Durham, NC 27710; e-mail: Thomas.Leblanc@duke.edu.

DOI: 10.1200/JOP.2011.000462

had been hospitalized at least once in the 6 months before palliative care referral. Forty-nine percent had a Palliative Performance Score (PPS) of 40% to 60%; 40% had PPS ≤ 30%. Although 81% had an estimated prognosis of ≤ 6 months, 58% were expected to live weeks to months. Thirty-three percent had no identified healthcare surrogate; 59% had no do-not-resuscitate order despite declining functional status and limited prognosis. Ninety-five percent reported ≥ 1 symptom, and 67% reported ≥ 3 symptoms; a substantial proportion did not receive treatment for symptoms.

Conclusions: Patients referred to community-based palliative care experience multiple often-severe symptoms that have been insufficiently addressed. They tend to have declining performance status. Earlier palliative care intervention could improve outcomes but will require delivery models that better coordinate inpatient/outpatient oncology and community-based palliative care.