Getting to Proven: Evaluating Quality Across All of Palliative Care

To the Editor:

Palliative care is great. As a clinical discipline and a scientific field, I believe—and many conversations around health care reform are now echoing—that palliative care embodies the best of patient-centered care. Our field comprises empathetic, compassionate, and dynamic clinicians, researchers, educators, and leaders who we are privileged to call colleagues. We are building our evidence base through clinical trials, qualitative studies, and health services research to balance the traditional art of our practice with the science needed to test and evolve our interventions. We pride ourselves in understanding the stories of patients and caregivers, in eliciting and respecting their values, and in addressing unmet needs across all areas of care, both medical (e.g., physical symptoms) and non-medical (e.g., spirituality and existential distress). Undeniably, the unique combination of committed clinicians and an expanding evidence base empowers us to infuse our own flavor of innovation into the traditional health care system. We are there for patients and families—both literally at the bedside and symbolically—in a journey of difficult decision making and goal setting. We take our time, carefully facilitating the conversations around issues of strength, areas for hope, and concerns for worry. We are “there” in every sense of the word. But I wonder, is “being there” enough to demonstrate the worth of our services and our discipline?

In an evolving world of health care reimbursement, we must prepare ourselves for a rapid transition from quantity-based services to quality-based care. This requires us to continue messaging our focus on “doing the right thing,” but with increased measurement rigor. Meeting these expectations necessitates identifying the gaps within the current measurement tools that evaluate how structures, processes, and outcomes of care align with our discipline’s goals. Then, as driven by a new world of continuous quality improvement where cyclical, proactive, and data-driven processes guide care improvement, we must address the known gaps in quality measurement that miss the complex, multidisciplinary, and cross-setting aspects of palliative care. This starts with creating and testing new quality measures, expanding past the current cohort to appraise all aspects of care in our field.

Daaleman et al. recently reported the validity and reliability of the Quality of Spiritual Care tool to evaluate quality of care processes within this domain. They provide a well-conducted framework for how quality measurement tools can be developed and tested in a palliative care setting. Moreover, they focus on family caregivers’ perceptions, collecting the voice and story of those who have expended enormous efforts to care for loved ones. This is methodologically unique in that it measures a critical component of palliative care beyond symptom assessment and management, emphasizes outcomes (e.g., caregiver perception of spiritual care), and starts to inform what “high-quality spiritual care” truly means (e.g., focus on satisfaction and value of spiritual care). As the authors comment, this is one of the first forays into developing quality measures for spirituality in palliative care.

Now is the time to develop the next generation of quality measures for our field, paying attention to: 1) the “procedures” we call our own (e.g., family meetings, goals of care discussions), 2) the multidisciplinary team members who perform multidomain assessments (e.g., chaplains, social workers, pharmacists), 3) the new
settings of care where quality measurement should be tailored (e.g., community-based palliative care), and 4) the care models that transition across generalist and specialist palliative care. Furthermore, we should expand into other important components of palliative care including transitions of care, support of caregivers, and patient and caregiver understanding of prognosis, among many others. We should be creative and rigorous in our approach, mirroring the methods from systematic research to evaluate generalizability and ability for implementation. Additionally, we should design quality measures that can inform dual goals of accountability (i.e., evaluating effectiveness of care for administrators and payers) and quality improvement (i.e., using data to inform areas for improvement) simultaneously. Moreover, we should develop the infrastructure to aggregate and compare our experiences, ultimately utilizing our collective wisdom to refine and revolutionize our best practices.

Palliative care is maturing as a discipline simultaneously with large-scale changes in accountability and reimbursement in health care. We are learning how to demonstrate our value in the language of cost avoidance and decreased hospital readmissions. We also are defining the quality and research questions that need to be answered to move our field forward. Moreover, collaborations with other membership societies and large-scale initiatives like the Virtual Learning Collaborative and Primary Palliative Care Consensus Statement between the American Academy of Hospice and Palliative Medicine and the American Society of Clinical Oncology are further defining best practices and methods for implementing those practices. These are excellent first steps to demonstrate that we, as palliative medicine professionals, take ownership of issues of quality for all who suffer with chronic and serious illnesses. Now, more than ever, the shifting winds of health care reform earmark a time where palliative care must transition from saying “we’re here” to “we’re great,” followed by one additional key phrase: “and here’s how we prove it.”

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References

The Bow Tie Model of 21st Century Palliative Care

To the Editor:

The World Health Organization’s definition of palliative care has evolved such that the recipient’s illness is no longer required to be deemed incurable. Palliative care is now described as an approach applying to “life-threatening illness” and “applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.” This modern definition aims to include patients at a stage in their illness when cure may be unlikely, but not impossible. Despite this evolution in understanding of our specialty, public perception may be lagging behind.

The benefits of early integration of palliative care are well established; however, the challenges of actually achieving early integration are, unfortunately, equally well recognized. Late referrals and inadequate resources are common in many palliative care programs and