

## VIEWPOINT

**Yael Schenker, MD, MAS**

Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, University of Pittsburgh, Pittsburgh, Pennsylvania.

**Robert Arnold, MD**

Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, University of Pittsburgh, Pittsburgh, Pennsylvania.

## The Next Era of Palliative Care

**In 1995, the pivotal SUPPORT** (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), involving more than 4000 patients, documented “substantial shortcomings in care for seriously ill hospitalized patients” while demonstrating no improvement in outcomes with a nurse-led communication intervention.<sup>1</sup> These negative results—published in *JAMA* and referenced in more than 1000 peer-reviewed publications—galvanized efforts to improve advanced illness care. Champions of these efforts became leaders in palliative care—an emerging field focused on improving quality of life and alleviating physical and psychological symptoms for patients with complex serious illness and their families.

Initially established as a consult service at a handful of teaching hospitals in the early 1990s, palliative care programs have witnessed substantial expansion over the past 2 decades.<sup>2</sup> This growth has been fueled by evidence that specialty palliative care improves outcomes for seriously ill patients and families. In response, professional guidelines now recommend

---

The next era of palliative care must embrace a broader focus on systems of care, measurement and accountability for palliative services, and national policy changes that promote universal provision of high-quality advanced illness care.

earlier and routine comanagement by palliative care specialists. Hospitals are also hiring more palliative care clinicians to staff busy consult services.

Yet 20 years after SUPPORT, little has changed for seriously ill patients, who continue to receive poor quality, high-cost care *without* being informed of likely treatment outcomes so that they would be able to make decisions that reflect their values.<sup>3</sup> This is not surprising, given that increases in palliative care services will never match vast and increasing palliative care needs. (Approximately 75% of people who die in high-income countries would benefit from palliative care. These needs will increase as the population ages.<sup>4</sup>) Palliative care workforce shortages are significant, access to palliative care is highly dependent on geography,<sup>2</sup> and referral patterns remain variable, with many patients and clinicians reluctant to use specialty palliative care services even when available.<sup>5</sup>

Palliative care specialists cannot be expected to have a significant, population-level influence through the traditional model of providing direct care to individual patients and families. The initial era of palliative care demonstrated

proof of concept—that is, that quality of care near the end of life can be improved. The next era of palliative care must embrace a broader focus on systems of care, measurement and accountability for palliative services, and national policy changes that promote universal provision of high-quality advanced illness care. Without these changes, it will not be possible to achieve the goal of improving the experience of patients with serious illness.

### Systems of Care

A palliative care consult is one approach to ensuring that seriously ill patients receive medical care that reflects their values and alleviates physical and psychological symptoms. However, more than two-thirds of hospitalized older adults must make major treatment decisions, most experience symptoms that require palliation, and many family members are burdened by the demands of surrogate decision making. If palliative care consultants cannot provide care for everyone in need, systems must be in place that clearly define the important role of palliative care specialists<sup>6</sup> while helping non-specialists provide compassionate patient- and family-centered care.

Quality improvement strategies that have successfully improved other health care outcomes could be applied to advanced illness care. These strategies involve focusing on a problem, identifying related and modifiable processes, and developing new protocols to achieve a desired outcome. For example, if the goal is to ensure that patients are able to make decisions about life-sustaining treatments that reflect their values, a quality

improvement approach may include training clinicians in appropriate communication skills, providing tools that support patient-centered goals of care discussions, developing policies to ensure that these discussions occur with appropriate clinicians at appropriate time points, and designing electronic health record changes to facilitate documentation of patient preferences. This type of approach, informed by input from diverse stakeholders and supported by health system leaders, demonstrates a system-wide commitment to patient-centered decision making that is more likely to yield widespread and sustained improvements in care than relying on specialty palliative care consults.

### Measurement and Accountability

System changes require measurement and accountability. The first step is to routinely measure outcomes that matter to seriously ill patients and their families. In the above example, this would mean tracking goals-of-care discussions and resuscitation status orders for seriously ill hospitalized patients. This quality improvement strategy could

### Corresponding

**Author:** Yael Schenker, MD, MAS, Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, University of Pittsburgh, 230 McKee Place, Ste 600, Pittsburgh, PA 15213 (schenker@upmc.edu).

be evaluated by assessing how often goals of care are documented in specific patient populations, as well as patient satisfaction and resource utilization before and after a system change. The second step is to provide feedback about these measures to individual clinicians and health care groups. In the same way that primary care physicians commonly receive feedback on their rates of diabetes and hypertension control, they should receive feedback on their rates of goals-of-care conversations with seriously-ill patients.

Nascent efforts to measure these outcomes have begun. The American Society of Clinical Oncology's Quality Oncology Practice Initiative currently includes quality measures with relevance to palliative care, such as adequate pain control, rates of chemotherapy administered within the last 2 weeks of life (lower is better), and documentation of advance directives (test measure). To influence care, however, programs like this need to be automated as part of the electronic health record, rather than require chart review, so that data can be collected on every patient and provided to individual clinicians on a regular basis.

These data should be linked with physician quality incentives. Hospitals, specific service lines, or clinicians who perform poorly may warrant deeper exploration of the data to understand how different patient populations or practice environments influence palliative care processes. Physicians with lower rates of goals-of-care discussions should receive additional training on how to have these difficult conversations.

Some data suggest that change in end-of-life care is occurring. For instance, Krumholz et al<sup>7</sup> recently reported that among Medicare beneficiaries, total hospitalization rates, average days hospitalized, and inpatient expenditures during the last 6 months of life declined substantially from 1999 through 2013.

### National Policy Change

Realizing the goal of improving the experience of serious illness will require national policy changes that promote provision of high-

quality serious-illness care. The recent move toward Medicare reimbursement for discussions about end-of-life preferences is an important step in the right direction. Systems that facilitate elicitation of patient values will not work unless financial incentives for clinical work reward delivery of patient- and family-centered care. Federal research funding must also support innovative efforts to improve quality-of-life and the quality-of-advanced-illness care. Although the National Institutes of Health (NIH) funding of palliative care research has increased in recent years, it grants less than 1% of its funds to palliative care research.<sup>8</sup> Moreover, the vast majority of serious illness care takes place outside of health care settings; yet, the United States spends less on social services relative to health care than virtually any other industrialized nation. Federal programs to increase support for family caregivers and expand access to programs like meals-on-wheels would help to improve patient and family experiences at home and reduce the need for palliative health care services.

To improve palliative care for patients with serious illness, 3 changes must occur. First, palliative care specialists need to develop skills in clinician behavior change, system change, and quality improvement. Second, health systems need to expand their focus to develop programs that measure and improve the quality of palliative care that every patient receives. Third, federal funding must be aligned with a national goal of improving the experience of seriously ill patients and their loved ones. In short, the field of palliative care has expanded substantially over the past 20 years by demonstrating the value of involving palliative care specialists earlier and more routinely in the care of seriously ill patients. Moving forward, palliative care is likely to have the greatest benefit by teaching others clinicians to provide patient and family-centered care, designing systems, and advocating for policy changes that help make the involvement of specialists less necessary.

#### ARTICLE INFORMATION

**Published Online:** September 3, 2015.  
doi:10.1001/jama.2015.11217.

**Conflict of Interest Disclosures:** All authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr Arnold reported that he is on the board of directors of Vital Talk, a not-for-profit organization that focuses on teaching clinicians communication skills when seeing seriously ill patients.

**Funding/Support:** Dr Schenker was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number KL2TRO00146.

**Disclaimer:** The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

**Additional Contributions:** We thank R. Sean Morrison, MD, and Diane Meier, MD (Icahn School of Medicine, Mount Sinai), and Deborah Seltzer for their comments on an earlier draft of this

manuscript. No compensation was received for their comments.

#### REFERENCES

1. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.
2. Morrison R, Meier D. A state-by-state report card on access to palliative care in our nation's hospitals. Center to Advance Palliative Care and the National Palliative Care Research Center. 2011. Available at <https://www.capc.org>. Accessed July 17, 2015.
3. Institute of Medicine. Dying in America: improving quality and honoring individual preferences near the end of life. 2014. Available at <http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>. Accessed July 17, 2015.
4. Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kalogi YE, Higginson IJ. How many people need palliative care? a study developing and comparing methods for population-based estimates. *Palliat Med*. 2014;28(1):49-58.
5. Schenker Y, Crowley-Matoka M, Dohan D, et al. Oncologist factors that influence referrals to subspecialty palliative care clinics. *J Oncol Pract*. 2014;10(2):e37-e44.
6. Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med*. 2013;368(13):1173-1175.
7. Krumholz HM, Nuti SV, Downing NS, Normand SL, Wang Y. Mortality, hospitalizations, and expenditures for the Medicare population aged 65 years or older, 1999-2013. *JAMA*. 2015;314(4):355-365.
8. Gelfman LP, Du Q, Morrison RS. An update: NIH research funding for palliative medicine 2006 to 2010. *J Palliat Med*. 2013;16(2):125-129.