I spend a lot of time thinking about the Affordable Care Act (ACA) and how it will affect the sickest, most vulnerable, and therefore most costly patients in the U.S. I practice in the relatively new interdisciplinary specialty of palliative medicine, which aims to improve the quality of life of people with serious, complex illnesses. (http://aahpm.org/) So all of my patients are living with profound fatigue, pain, shortness of breath, financial and family stresses, and mountains of worry. The ACA's focus on quality over quantity could increase attention to the needs of such patients. Or, with its twin focus on reducing out-of-control spending, the ACA might prompt a race to the bottom, as necessary — but costly — treatments are summarily avoided.

How do we ensure that the neediest patients receive care that is truly valuable to them, instead of the usual merry-go-round of costly emergency room visits and hospitalizations for problems that can — and should — be managed at home? The answer to this question lies in defining how the concept of “value” applies to patients who need palliative care, devising a system for rigorously measuring that value, and then implementing it in practice.

**VALUE IN THE ERA OF THE ACA**

We know that a high-value health intervention simultaneously improves quality and reduces costs. Think of clean drinking water and vaccination, which save millions of lives at an extremely low cost per person. A quintessential low-value intervention is one that misapplies the power of modern medical care. Think of ICU stays for people with end-stage dementia or chemotherapy for cancer patients who are near death — very expensive treatments with no possibility of improving either quality or quantity of life. The ACA tightly links the goals of improving quality of care while reducing costs; that means measuring quality accurately and avoiding the often-perverse financial incentives of fee-for-service medicine. The ACA has begun to move the health care system in this direction. So why I am I worried?

My concern has to do with the profile of the patients I serve. Health care spending is highly concentrated, as it should be, on the people who are most ill and have the most-complex needs. In fact, the sickest 5% of us drive half of all health spending. Anyone running a health care system and trying to deliver value in the era of the ACA should obviously focus on these patients. But it is the nature of that focus that makes all the difference. The problem is not that caring for very sick patients costs more than caring for healthy people (of course it does!); it’s that how we spend that money typically ignores the top priorities of the very ill and their families. To appreciate those priorities requires an understanding of my medical specialty: palliative care.

**DEFINING VALUE IN PALLIATIVE CARE**

Working alongside a seriously ill patient’s regular medical team, the palliative care clinician
focuses on relieving pain, symptoms, and other stresses. Studies of palliative care show that it improves patients’ and their families’ quality of life and reduces hospitalization and use of emergency services. (http://www.nejm.org/doi/full/10.1056/NEJMsb1305469) A recent study of cancer patients also documented better survival rates for patients who received both palliative care and optimal cancer care than for those who received only the latter. (http://www.nejm.org/doi/full/10.1056/NEJMoa1000678) In short, the evidence shows that palliative care works. How do we then achieve the greatest value with this effective care, giving patients neither less nor more than what they need?

We start by asking patients and their families what matters to them, not focusing on the disease alone. We recognize that for patients with serious, progressive (usually chronic) conditions, as their illness evolves, what matters to them and their families also changes. Most patients value care that helps them stay at home and remain independent for as long as possible; that does not result in financial bankruptcy; and that tries to reduce suffering of all kinds — bodily pain, difficulty breathing, nausea, depression, anxiety, and existential and spiritual distress. Palliative care clinicians, working alongside the patient’s regular doctors, provide that support directly to patients and their often exhausted, overwhelmed family caregivers. But for that support to become the standard of practice, it must be bolstered by a system for measuring quality and outcomes, tailored to the unique needs of the palliative-care patient population and consistent with the value-based goals of the ACA.

MEASURING THE VALUE OF PALLIATIVE CARE

We know that cost-control efforts must focus on the sickest and costliest patients. How do we ensure that those efforts sweep out the unnecessary services (thereby achieving desired savings) while preserving and enhancing what very ill patients and their families need and value? The solution is a rigorous, transparent set of quality measures that hold providers and payers to standards that protect this vulnerable group. But the science of quality measurement is not advanced enough to measure what matters most to these patients, in part because patients’ preferences shift as illness progresses and because we don’t yet know how to allocate resources to achieve patients’ care-related goals.

The story of 89-year-old Joseph Andrey, recounted in the New York Times, illustrates the dilemma. (http://www.nytimes.com/2014/09/26/nyregion/family-fights-healthcare-system-for-simple-request-to-die-at-home.html?_r=1) Andrey’s only goal was to remain at home with the 24-hour personal-care support he needed until he died. Neither Medicare nor Medicaid (he had both) would cover this service, and his only daughter worked full-time as a schoolteacher. So Andrey spent the last two years of his life cycling among hospitals, nursing homes, and rehabilitation facilities. The costs: millions in taxpayer dollars and untold suffering for both the patient and his exhausted daughter.

Andrey’s story makes clear that knowing a patient’s goals isn’t enough. We must also align the supports and resources necessary to honor them. Specifically, we have to define the measures that would reveal that Mr. Andrey’s exorbitantly costly, primarily institutional care was of poor quality, precisely because it failed to honor his known and consistent preference to receive care in his own home.

How do we begin to encourage and measure the delivery of medical care that is of high value to patients with serious illness? In addition to following helpful advice from the American Academy of Hospice and Palliative Medicine, I suggest four tactics:

1. Explicitly ask patients and their families what matters most to them, and ensure that this information is recorded, made available in the medical record, and actively used by all involved parties in decision making about care.

2. Require that all clinicians (doctors, nurses, social workers, and others) receive basic training and certification in pain and symptom management, communication, and coordination of care across time and settings.

3. Document and analyze the perverse financial incentives that impede delivery of care that is consistent with the priorities and needs of patients and their families.
4. Measure and facilitate access to high-quality palliative care services for all people with serious illness, regardless of age, stage of disease, or care setting. The challenge we face is obvious. If quality measurement is to achieve its purpose, the health care system must define and measure the outcomes that matter to the people at highest risk of neglect, undertreatment, overtreatment, and suffering. Cost containment is urgent and necessary. But so is protection for the patients most in need of care and least able to advocate for themselves.