By Bill Novelli and Raca Banerjee

Advanced Illness Care: We Can Do Better

How Medicare can support dignity and compassion near the end of life.

There's a wistful story noised about among gerontologists that everyone should live in good health to a ripe old age, well into their nineties, and then have life end with a quick bullet—fired by a jealous lover. But we all know that is *not* the way most people in America head off into the Great Beyond. Too much of the time, in our current American culture, dying can be protracted and especially painful, isolating, and costly.

That's often the reality of dying—with or without—the support and services provided by our health system today. But what is it that people actually want when they are seriously ill and know they may be approaching life's end? Research tells us they want to be at home, with family and friends—to have their pain managed, their spiritual wishes and needs respected and honored, and, to be assured that those who love them are not emotionally and financially devastated in the process.

So there is a great deal of difference—a very large gap—between the kind of care and treatment people say they want at the end of life and what our society and health system provide. Things have to change, or they will get worse instead of better. America's population is aging rapidly and as this occurs, more and more people are living with multiple chronic diseases, with the limitations of managing personal care, and of where they are able to live and with what degree of independence.

And then there's technology, in many ways the great blessing of our age. But in the world of serious illness, technology has the perverse potential to keep people "alive" regardless of their condition or what they want.

Though anyone can be seriously ill, advanced illness is common among the frail elderly and occurs when one or more chronic conditions progress to the point where general health and functioning decline, response to treatment is reduced, and care needs increase. Trips to the emergency room and hospitalizations frequently occur, prognosis and treatment plans may become uncertain, patient goals and preferences may change, and often there is stress and crisis among patients and their families. Along with this, people must struggle to navigate a fragmented care delivery system that is unprepared to respond to their goals and preferences in the latter stages of life.

It doesn't have to be this way; we can do much better. We can create the change needed so that people with advanced illness receive comprehensive, high-quality, person- and family-centered care that honors their dignity and is consistent with their goals and values. How? By empowering consumers to engage in comprehensive, in-depth conversations with their providers and families regarding care goals, wishes, and preferences, working to reform the care delivery system, improving public and private policies, and enhancing provider capacity.

The Evolution of End-of-Life Care

The landscape of end-of-life care has certainly improved over the past decade. Since the release of the 1997 Institute of Medicine (IOM) report, *Approaching Death: Improving Care at the End of Life*, hospice has become mainstream, both inpatient and community-based palliative care programs have sprung up nationwide, and innovative care delivery models have been developed to address the needs of this population and focus care on the person, rather than the patient, going through the medical system (IOM, 1997).

During the passage of health reform a few years ago, political controversies surrounding the language and messaging of advance care planning led to misguided notions regarding government panels and end-of-life care decisions. This turned the debate into one that was toxic, strikingly partisan, and devoid of rational, open discussion.

But we have come a long way since then. Recently, there has been a renewed sense of interest and engagement in this issue that is unmarred by false perceptions and suspect accusations regarding the role of government in end-of-life care.

In September 2014, the IOM published a report to reassess the status of end-of-life care in America—*Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. While the study notes remarkable progress since the 1997 report's release, it also pinpoints key gaps where improvement is needed in clinician–patient communication and advance care planning, professional education and development, policies and payment systems, and public education and engagement (IOM, 2014).

The 2014 report recommends policies and strategies to support care delivery that is high-quality, person-centered, and financially sustainable. The bottom line rings clear: there is a great need to improve end-of-life-care delivery across the board. And there are multiple opportunities to do so.

The report's release signals a broader shift in the political and legislative climate on end-of-life care. The issue is gaining greater traction and credibility among leaders in the current Administration and Congress; both are addressing regulatory reform and policy mechanisms to enhance and improve care-delivery structures. The challenge before us is to expand and capitalize on these opportunities to truly transform advanced illness and end-of-life care in the United States.

The Role of Medicare in End-of-Life Care

By 2050, an estimated 20.6 percent of Americans will be age 65 or older (He et al., 2005). With the aging of the Baby Boom Generation and rapidly changing U.S. demographics, Medicare increasingly will play a greater role in care delivery.

In 2010, more than a third of Medicare beneficiaries experienced four or more chronic conditions. Those with four to five conditions cost $12,174 in per capita spending, and those with six or more chronic conditions averaged nearly $32,658 in per capita spending (Centers for Medicare & Medicaid Services [CMS], 2012).

Many of these individuals often report a mismatch between their needs and the care the system provides—even before the end of life. Older adults may die in a hospital or care facility rather than at home, often due to a misunderstanding of care goals and preferences, or because of care transitions that are poorly coordinated and executed. One study noted a concordance rate of only 37 percent between an individual's preferred versus actual site of death (Fischer et al., 2013).

These figures bring to light a number of underlying issues in our care delivery system. How do we ensure that all Americans receive the kind of end-of-life care that honors their individual goals, wishes, and preferences? Moreover, what is the role of Medicare in delivering this kind of care?

Over the past decade, multiple new models and approaches have been developed to better address end-of-life care, increase patient satisfaction and longevity, and, as a result, lower costs by reducing unwanted and unnecessary medical tests and procedures. Here, Medicare can play a pivotal role in enhancing the quality and coordination of care delivery, ensuring access to a full and comprehensive range of care services and supporting policies that are sustainable and responsible in the long run.

Strengthening Benefits and Services

Over the past few decades, Medicare has been a key player in developing and standardizing innovative strategies and models of care. The Hospice Benefit (established in 1982 and made permanent in 1986) developed a model of care delivery that is compassionate and properly addresses and responds to the complex physical, social, and emotional needs of this population. The basic philosophy and principles of hospice are aligned with what individuals want as they reach the end of life.

The hospice approach focuses on patient self-determination and allows individuals to make their own treatment choices and decisions. Its framework integrates and coordinates care across all settings, promotes ongoing collaboration and care integration with the community, and ensures that an individual continuously discusses and reviews his or her goals and preferences of care. This model uses a team of interdisciplinary professionals (including physicians, nurses, social workers, chaplains, and others) to tailor the care experience to the individual at the end of life. This form of care delivery is focused on increasing quality of life. Studies have also demonstrated that median survival periods on average are higher for individuals enrolled in hospice—by up to twenty-nine days (Connor et al., 2007). The hospice model eases the transition into the end of life for both the individual and his or her loved ones, and relieves much of the emotional burden and suffering during the process.

The use of hospice care has grown tremendously over the past decade. As the industry continues to evolve and expand, closely monitoring the growth and progress of programs will become key in developing future reforms. Implementing quality metrics that can properly assess individual and family experiences of care, pain and symptom management, access to nursing care, and other factors will be essential to evaluating program performance and ensuring high-quality care for all individuals at the end of life.

Technology has the perverse potential to keep people "alive" no matter their condition or what they want.

To maximize the potential impact of hospice care, beneficiaries should be made fully aware of and have access to these kinds of services. Supporting timely and appropriate referrals to hospice is key to ensuring that individuals receive high-quality care when they need it most. To this end, the Hospice Benefit can be improved to minimize restrictive administrative and regulatory barriers. One step would be to revise the "six-month eligibility" rule requiring a physician to make a six-month prognosis for an individual before he or she is able to receive hospice care. Extending this six-month period would allow beneficiaries to receive such care without being limited by a strict criterion.

In addition, under the current benefit structure, most individuals who receive care through hospice are required to forgo curative care. Allowing curative care to be provided in combination with hospice care offers a broader, more comprehensive range of services for individuals and allows for greater freedom in determining treatment paths and outcomes. A number of innovative programs have already begun to test this "concurrent care" model across the country.

In March 2014, the Center for Medicare & Medicaid Innovation (CMMI) announced the Medicare Care Choices Model that would allow providers across the nation to experiment with this model of concurrent care delivery (CMMI, 2014). As results from the first round of implementation come in, the evidence base for these innovative models and approaches will continue to expand and drive lasting, high-impact delivery reform in this area.

In addition to strengthening the Hospice Benefit, policy makers can support Medicare policies that promote effective, appropriate pain management, institutionalize palliative care across care settings (including hospitals, health systems, hospice, and others) and ensure strong, sustainable systems for reimbursement for palliative care services. Palliative care, as defined in the IOM *Dying in America* report, "provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. . . . It encompasses hospice care, basic (or 'primary') palliative care, or specialty palliative care" (IOM, 2014). Palliative care is an essential component of care delivery as individuals develop serious advanced illness and ultimately reach the end of life. As such, it should be properly provided for and reimbursed.

Voluntary Advance Care Planning

A study published in January 2014 noted that, out of a survey representation of nearly 8,000 Americans, only 26.3 percent of respondents had completed an advance directive between the years 2009 and 2010 (Rao et al., 2014). Engaging beneficiaries in discussions about their goals and wishes allows for greater communication between individuals and their physicians.

Medicare can support the adoption of incentives for providers and payers to support voluntary advance care planning and allow for advance directives to be carefully discussed, documented, and regularly available in an easy-to-access, straightforward manner. More importantly, these directives should be constantly revised and renewed. As we grow older, our care goals, wishes, and preferences evolve over time and it is essential to ensure these records are up-to-date and reflect our most recent choices and preferences. Legislative proposals such as the Personalize Your Care Act offer Medicare and Medicaid coverage for voluntary advance care planning once every five years, or any time there is a change in health status. This proposal also offers state grants to either establish or expand Physician Orders for Life Sustaining Treatment (POLST) programs, which allow individuals with serious illness to provide specific instructions on treatment choices and preferences, given their advanced diagnosis (U.S. Congress, 2013).

What is the role of Medicare in delivering the kind of end-of-life care that honors individual goals, wishes, and preferences?

In August 2014, the American Medical Association proposed CMS adopt Current Procedural Terminology (CPT) codes to reimburse physicians for voluntary advance care planning. Adopting these codes would spur providers and payers to offer consultations regarding patient goals, values, and preferences. Specifically, these codes would reimburse for "advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified healthcare professional; face-to-face with the patient, family member(s), and/or surrogate" (Federal Register, 2014).

Although these codes address the issue of advance care planning through an administrative lens, they are an important first step in setting a precedent for providers and insurers to ensure that beneficiaries have access to these discussions and services. Following the initial announcement of these CPT codes, CMS requested stakeholder input to gather comments on whether the codes should be reimbursed. These codes were eventually adopted but denied for reimbursement in January 2015. However, many private insurers are beginning to pay for voluntary advance care planning and will hopefully pave the way for the public sector.

Other methods also can be used to encourage and support voluntary advance care planning. Providing thorough, comprehensive planning materials in the *Medicare & You Handbook* (http://goo.gl/Nx9jOx), for instance, would provide an avenue for beneficiaries to better understand how to create and continuously update an advance directive. Advance care planning consultations also are available through the initial "Welcome to Medicare" primary care visit offered to beneficiaries and should be widely used and promoted.

Quality Measurement and Reporting

CMS can work closely with well-established private-sector entities, such as the National Quality Forum, to develop consensus on key quality metrics to be adopted by Medicare to assess the quality of care delivered at the end of life (including measures that include quality, cost, access, and patient and family satisfaction).

Measures on quality help assess whether advanced illness care is resulting in improved patient outcomes and whether any changes result in adverse outcomes. Measures related to access to the continuum of care are essential for ensuring that all groups and ethnicities receive high-quality care that meets their needs. Measures of satisfaction should include perceptions of shared decision-making (with clinicians), access to medical and related social resources (e.g., care at home, respite), care coordination, and pain and symptom management. Cost data are currently collected for the Medicare population, which includes not only those older than age 65 but also those with certain chronic or debilitating diseases (e.g., kidney failure requiring dialysis).

The systemized collection and reporting of quality measures are essential to building the evidence base for effective interventions, assessing program progress and development, and driving effective payment and delivery reform. The passage of the Improving Medicare Post-Acute Care Transformation Act (IMPACT Act) in October 2014 signified a resounding theme throughout the stakeholder community—that there was a greater need for standardized post-acute assessment data across all post-acute care settings. The law will allow Medicare to compare quality performance across settings, improve discharge planning, and use this data to guide and inform future payment and delivery reform efforts (U.S. Congress, 2014).

Goals and Next Steps

Medicare has played a profound role in the improvement of advanced illness care in America, but much more can and must be done to achieve greater progress. The goals are to strengthen Medicare benefits and policies, promote voluntary advance care planning, and encourage public reporting of quality measures in order to both continuously assess and improve the status of end-of-life care in our nation.

Building strategic partnerships and cross-sector collaborations and fostering workable bipartisanship are essential to strengthening Medicare and providing comprehensive, high-quality care for individuals in the advanced stages of illness and nearing the end of life.

A number of innovative groups and providers across the country have been piloting, testing, and developing innovative approaches to improving care delivery for this population. The Coalition to Transform Advanced Care (C-TAC) serves as a convener on these issues and as a catalyst for reform by working closely with policy makers at the federal level.

C-TAC has two resources to move this discussion forward: a comprehensive federal policy agenda to drive policy change and a book, *A Roadmap for Success: Transforming Advanced Illness Care in America* (C-TAC, 2015). Learn more about these initiatives and access the book at www.thectac.org/.

Ultimately, this is an issue that affects us all: everyone has a story about a friend or relative that either had a positive or negative experience at the end of life. Statistics, policies, and metrics are, of course, important, but it is the people behind all this that matter most. And as we brace for the onrushing wave of older Americans with progressive chronic diseases, there is much that we can and must do to provide a compassionate and dignified experience for all individuals at the end of life.

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References

Centers for Medicare & Medicaid Services. 2012. “Chronic Conditions Among Medicare Beneficiaries.” www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-ConditionsDownloads/2012Chartbook.pdf. Retrieved December 8, 2014.

Center for Medicare & Medicaid Innovation (CMMI). 2014. “Medicare Care Choices Model.” http://innovation.cms.gov/initiatives/Medicare-Care-Choices/. Retrieved December 8, 2014.

Coalition to Transform Advanced Care (C-TAC). 2015. *A Roadmap for Success: Transforming Advanced Illness Care in America*. Palo Alto, CA: Issuu Digital Publishing.

Compassion & Choices. 2014. “25 Million Older Americans Have Experienced Unwanted or Excessive Medical Treatment, Survey Suggests.” www.compassionandchoices.org/2014/07/29/25-million-older-americans-have-experienced-unwanted-or-excessive-medical-treatment-survey-suggests. Retrieved October 19, 2014.

Connor, S. R., et al. 2007. “Comparing Hospice and Non-hospice Patient Survival Among Patients Who Die within a Three-year Window.” *Journal of Pain Symptom Management* 33(3): 238–46.

Federal Register. 2014. *Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule, Clinical Laboratory Fee Schedule, Access to Identifiable Data for the Center for Medicare and Medicaid Innovation Models & Other Revisions to Part B for CY 2015*. Washington, DC: U.S. Department of Health and Human Services, CMS. 79 FR 67547. http://federalregister.gov/a/2014-26183. Retrieved December 12, 2014.

Fischer, S., et al. 2013. “Where Do You Want to Spend Your Last Days of Life? Low Concordance Between Preferred and Actual Site of Death Among Hospitalized Adults.” *Journal of Hospital Medicine* 8(4): 178–83.

He, W., et al. 2005. “65+ in the United States.” www.census.gov/prod/2006pubs/p23-209.pdf. Retrieved December 4, 2014.

Institute of Medicine (IOM). 1997. *Approaching Death: Improving Care at the End of Life*. Washington, DC: The National Academies Press.

IOM. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press.

Rao, J. K., et al. 2014. “Completion of Advance Directives Among U.S. Consumers.” *American Journal of Preventive Medicine* 46(1): 65–70.

United States Congress. 2013. “Personalize Your Care Act of 2013.” H.R. 1173, 2013. 113th Congress. Washington, DC: U.S. Government Printing Office. www.congress.gov/bill/113th-congress/house-bill/1173. Retrieved December 5, 2014.

United States Congress. 2014. “Improving Medicare Post-Acute Care Transformation Act” (IMPACT Act of 2014), H.R. 4994, Pub. L. 113–185. 113th Congress. Washington, DC: U.S. Government Printing Office. www.govtrack.us/congress/bills/113/hr4994. Retrieved December 8, 2014.