



An advisory on safety & quality issues

End-of-life care: A patient safety issue

Issue:

Patient safety and end-of-life care must not be, and are not, mutually exclusive. End-of-life issues are crucial for maintaining patient safety, which is a central aim of quality. The American Psychological Association defines end of life as that time period when health care providers would not be surprised if death occurred within about six months. End of life is the expected last days, weeks or months of life for patients with advanced or incurable disease or devastating injury. Older Americans with chronic illness think about how they would prefer their lives to end, and want a “good death,” without burdensome pain, symptoms and technology.

End-of-life care has emerged as a patient safety issue in part due to the high intensity care that is delivered at the end of life, including increased hospitalizations and more days in intensive care units. A 2010 Dartmouth study of elderly cancer patients nearing death found that 9 percent had a breathing tube or other life-prolonging procedure in the last month, and at most academic medical centers, more than 40 percent of the patients saw 10 or more doctors in the last six months of their lives.¹ Yet a 2010 study in the *Journal of Palliative Medicine* found that only 15 percent to 22 percent of seriously ill elderly patients had their preferences for end-of-life care in their medical records.² A 2011 survey conducted by the California Healthcare Foundation found that 82 percent of respondents said that written end-of-life wishes were important, yet only 23 percent had done so; almost 80 percent wanted to talk with a doctor about end-of-life issues but only 7 percent had done so.³ In addition, a survey conducted by The Conversation Project in 2013 (over 2,000 respondents age 18 and over in the U.S.) indicated 90 percent of Americans think talking about end-of-life wishes is important, yet less than 30 percent have had the conversation.⁴

The ‘silver tsunami’

Over the last two decades, life expectancy for those over age 65 has increased by two years. However, over half of Americans over age 65 are disabled and living with major chronic disease(s).⁵ Between 2010 and 2050, the population ages 65 and older will double, from about 40 million to 84 million people. The number of people ages 80 and older will nearly triple over these years from about 11 million to about 31 million, while the number of people in their 90s and 100s is projected to quadruple from 2 million to 8 million by 2050. This has been called the “silver tsunami” and is characterized as a major public health challenge.⁶

Interestingly, a recent analysis of Medicare spending noted that the increase in Medicare per capita spending, by age, for all Medicare beneficiaries over age 65 is not entirely attributable to end-of-life care nor to higher death rates among older beneficiaries. Medicare per capita spending is considerably higher for people who die during the year than people who survive the entire year (\$33,486 versus \$8,647 in 2011) and accounts for a disproportionate share of Medicare spending, yet the increase in spending by age is not entirely due to higher spending at the end of life.⁷

Debate surrounding end-of-life care

During the debate surrounding the Patient Protection and Affordable Care Act in August 2009, the words “death panels” emerged, with purposeful intent, to convey that individual choice in how one faces dying and death would be co-opted by some unseen federal bureaucracy that, based on a subjective judgment of a patient’s “level of productivity in society,” would determine if they are worthy of health care.

The Centers for Medicare & Medicaid Services attempted to authorize payment for counseling on advance care planning as part of annual wellness visits provided for under the Affordable Care Act. This provision was to go into effect on Jan. 1, 2011. By Jan. 4, the administration had withdrawn this provision. Doctors would still be free to talk with patients about living wills, hospice care, or other end-of-life concerns, but they could not bill Medicare for this service.⁸

(Cont.)



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In a proposed regulation released July 8, 2015, CMS introduced two new billing codes – previously recommended by the American Medical Association – for advance care planning provided to Medicare beneficiaries. If the regulation becomes a final rule, these new billing codes would be available to physicians and other qualified health professionals starting Jan. 1, 2016. CMS will release the final rule for the 2016 Medicare physician fee schedule later this year.

As a result of the ongoing debate regarding end-of-life decision-making, in 2014, the Institute of Medicine published [*Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*](#) that finds improving the quality and availability of medical and social services for patients and their families might not only enhance quality of life through its end but also may contribute to a more sustainable health care system.⁹ The IOM reports calls for:

- Coverage, by both government and private health insurers, of comprehensive care for patients with advanced serious illnesses who are nearing the end of life.
- The development of quality metrics and standards for clinician-patient communication and advanced care planning, with insurance reimbursement tied to performance on these standards.
- Strengthening clinical training and licensing/credentialing requirements in palliative care.
- Federal and regulatory action to establish financial incentives for integrating medical and social services for people nearing the end of life, including electronic health records that incorporate advanced care planning.
- Widespread efforts to provide information to the public on the benefits of advance care planning, and the ability for individuals to choose their own course of treatment.

Failures in end-of-life care

Most patients prefer to avoid being hospitalized at the end of life only to have their wishes denied by health care providers. While most end-of-life care is provided by subspecialists, a 2014 study finds that doctors' attitudes toward advanced planning has not changed in 23 years. While doctors favor advanced directives, they favor them less compared to patients, and use them infrequently.⁶ Documents describing physician orders for life-sustaining treatment (POLST) can be confusing, presenting a risk to patient safety.¹⁰

As with most sentinel events and patient safety events, the root causes of end-of-life care failures include teamwork failures, lack of safety culture, and poor communication. These root causes are manifested by: multiple health care professionals caring for the patient; variations in communications that occur between disciplines and settings; variations in end-of-life practices; and lack of standardized communications protocols, templates and order sets.

A recent review of patient safety and end of life reports that common end-of-life and patient safety issues include: inappropriate pain medications; medication errors, especially those involving high alert medications; inadequate pain management; overmedication; delirium; falls; pressure ulcers; and hospital-acquired infections and other conditions. More specific key issues include: poorly controlled pain; management and diagnostic errors; no bowel regimen for patients who experience constipation due to opioids; procedures or treatments where the risk exceeds the benefits; and team members not communicating with each other or the patient and family during a change in the patient's condition or situation.¹¹

Safety Actions to Consider:

Health care organizations can help protect patients from potential harm and provide better, higher quality end-of-life care by doing the following:

Create a framework for classifying patient safety practices in end-of-life planning focused on communication and care planning. These interventions may include regulatory and legal dimensions, physician orders for life-sustaining treatment (POLST), required do-not-resuscitate (DNR) discussions, documentation of advanced directives, availability of hospice and palliative care, end-of-life training for providers of care, and promoting care providers to establish goals of care with patients and families, as well as having goals of care discussions themselves.¹²

Support and train clinicians to conduct advance care planning, to ensure that the planning is what matters to the patient, and that the dignity of the patient is maintained and respected. Recommending or proceeding with procedures or treatments that are not consistent with what matters to the patient is a patient safety issue that could and does lead to harm and sentinel events (a patient safety event that reaches a patient and results in death, permanent harm, severe temporary harm, or intervention required to sustain life).¹³

Advanced care planning involves multiple steps designed to help individuals:

- Learn about the health care options that are available for end-of-life care
- Determine which types of care best fit their personal wishes
- Share their wishes with family, friends and their physicians

Provide clinicians with the information they need to conduct advance care planning conversations with their patients. Patients who have already considered their options may need only one advance care planning conversation with their physician. However, experts state that frequently patients may require a series of conversations with their physician or other health professionals to clearly understand and define their end-of-life wishes.¹⁴ A helpful resource published by the Institute for Healthcare Improvement, in partnership with The Conversation Project, is a white paper entitled “Conversation ready”: A framework for improving end-of-life care.¹⁵ The five principles that form the framework are:

- **Engage** with patients and families to understand what matters most to them at the end of life.
- **Steward** information about each patient’s end of life wishes as reliably as we do allergy information.
- **Respect** people’s wishes for care at the end of life by partnering to develop a patient-centered plan of care.
- **Exemplify** this work in our own lives, so that we finally understand the benefits and challenges.
- **Connect** in manner that is culturally and individually respectful of each patient. Patient-centered, end-of-life care must account for cultural influences, such as religion, ethnicity, socioeconomic status, educational levels and location.

This framework supports patient-centered care and patient safety at the end of life that includes: the patient; documenting that advanced planning has occurred; as well as doctors who honor, implement and facilitate the patient’s advance directives, and respect what matters to the patient.

Resources:

1. DC Goodman, et al: [A report of the Dartmouth Atlas Project: Quality of end-of-life cancer care for Medicare beneficiaries, regional and hospital-specific analyses](#). The Dartmouth Institute for Health Policy & Clinical Practice, Nov. 16, 2010 (accessed July 14, 2015)
2. VY Yung, et al: Documentation of advanced care planning for community-dwelling elders. *Journal of Palliative Medicine*, 21(10);13(7):861-867
3. Lake Research Partners and the Coalition for Compassionate Care of California: [Final Chapter: Californians’ attitudes and experiences with death and dying](#). California Healthcare Foundation, Oakland, California; February 2012 (accessed July 12, 2012)
4. The Conversation Project: [Cambia Health Foundation collaboration supports The Conversation Project with \\$161,000 grant to create virtual conversation ready Community Resource Center](#), September 18, 2014 (accessed July 14, 2015)
5. DM Cutler, et al: [Evidence for significant compression of morbidity in the elderly U.S. population](#). The National Bureau of Economic Research, Working Paper No. 19268, August 2013 (accessed July 14, 2015)
6. VS Periyakoil, et al: Do unto others: Doctors’ personal end-of-life resuscitation preferences and their attitudes toward advance directives. *PLoS ONE*, 2014;9(5):e98246. doi:10.1371/journal.pone.0098246
7. T Neuman, et al: [The rising cost of living longer: Analysis of Medicare spending by age for beneficiaries in traditional medicare](#). The Henry J. Kaiser Family Foundation, Jan. 14, 2015 (accessed July 12, 2015)
8. Department of Health and Human Services, Centers for Medicare & Medicaid Services. [Federal Register, Vol. 76, No. 6, Jan. 10, 2011, Rules and Regulations](#) (accessed July 13, 2015)
9. Institute of Medicine: [Dying in America: Improving quality and honoring individual preferences near the end of life](#). Sept. 17, 2014 (accessed July 13, 2015)

10. FL Mirarchi, et al: TRIAD VII: Do prehospital providers understand physician orders for life-sustaining treatment documents? *Journal of Patient Safety*, March 2015;11(1)
11. SM Dy et al: Patient Safety and End-of-Life Care: Common Issues, Perspectives, and Strategies for Improving Care. *American Journal of Hospice & Palliative Medicine*® 1-6, 2015
12. SM Dy et al: A framework for classifying patient safety practices: results from an expert. *BMJ Quality & Safety*, 2011;20:618e624 doi:10.1136/bmjqs.2010.049296
13. The Joint Commission: Comprehensive Accreditation Manuals, [Patient Safety Systems chapter](#), 2015, Oakbrook Terrace, Illinois (accessed July 14, 2015)
14. P Belluck: [Coverage for end-of-life talks gaining ground](#). *The New York Times*, Aug. 30, 2014 (accessed July 14, 2015)
15. AK McCutcheon, et al: [“Conversation ready”: A framework for improving end-of-life care](#), IHI White Paper. Cambridge, Massachusetts: Institute for Healthcare Improvement; 2015 (accessed July 14, 2015)

Other resources from The Joint Commission:

[Speak Up: What you need to know about your serious illness and palliative care](#)

[Speak Up: Tips for your doctor's visit](#)

[Speak Up: Know your rights](#)

Note: This is not an all-inclusive list.



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