

A Conversation for the Holidays: Part II

“What Matters to You”

Last year, I wrote an editorial entitled “A Conversation for the Holidays: The Conversation Project.”¹ The aim was to encourage readers to take some time during family visits to discuss a topic often left unspoken. End-of-life care, or health care choices when the future is uncertain, is often not discussed. These are not easy conversations. We have all avoided them, personally and professionally. These are frightening discussions, and we have all botched them many times. However, we have significant new knowledge on this topic.

As we approach the holiday season again, the subject is worthy of continued discussion, with an update about what has transpired over the past year.

Remarkably, many health care providers have found new courage to not only talk about this, but also share tools that help health care providers and families begin the conversation. Through education, research, community involvement, and political action, we are seeing a culture change around this topic.

The past year has shown tremendous promise as health care professionals have shifted the conversation. We are beginning to ask patients, “What matters to you?” rather than “What is the matter with you?”

2014

The Institute of Medicine (IOM), now The National Academy of Medicine, released an extraordinary report, one that every health care provider should read. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* was released on September 17, 2014, complete with a live video discussion produced by the IOM, discussing the tenets of the report.^{2,3} This groundbreaking report was received with excitement, relief, and tremendous support—as it righted the controversy surrounding the politicization of end-of-life care during the early years of the Affordable Care Act.

The report validates and confirms that end-of-life planning has a very important role. Such plans can help providers figure out the right balance between quality of life

and pursuing intensive treatments. The summary of the report begins with this introduction:

For patients and their loved ones, no care decisions are more profound than those made near the end of life. For the millions of Americans who work in or with the health care sector—including clinicians, clergy, caregivers, and support staff—providing high-quality care for people who are nearing the end of life is a matter of professional commitment and responsibility. Health system managers, payers, and policy makers, likewise, have a responsibility to ensure that end-of-life care is compassionate, affordable, sustainable, and of the best quality possible.

A substantial body of evidence shows that broad improvements to end-of-life care are within reach. In *Dying in America*, a consensus report from the IOM, a committee of experts finds that improving the quality and availability of medical and social services for patients and their families not only could enhance quality of life through the end of life, but may also contribute to a more sustainable care system.³

Immediately following the release of *Dying in America*, Dr Atul Gawande’s newest book, *Being Mortal: Medicine and What Matters in the End*, hit bookstores on October 7, 2014.⁴ It has remained on national best sellers list since.

Gawande, a surgeon and author, wanted to talk about dying because he realized that he did not know how, and many of his colleagues felt the same. To find out more about how to deal with mortality, a subject not taught in medical school, he interviewed more than 200 people about aging, living with terminal illness, and dying.

Dr Gawande spent much of the year speaking at multiple forums to discuss his book, including sessions at IOM, Institute for Healthcare Improvement (IHI), international forums and local conferences. Many spiritual, education, and medical groups organized book reads and discussion groups. Nursing students in the Boston College IHI Open School chapter sponsored a book read and developed discussion groups, scenarios, and an educational seminar to model new language and approaches introduced by

Dr Gawande’s work. Similar work continued in academic settings and health care organizations worldwide!

2015

On February 10, 2015, Dr Gawande, and the work described in his book, was featured in an hourlong televised program on Frontline (<http://www.pbs.org/wgbh/pages/frontline/being-mortal/>).

Mainstream media began to report about the new conversations and introduce the public to new studies including one done at Massachusetts General Hospital in Boston that has provided encouraging results. Patients with stage IV lung cancer were randomized to either get the usual oncology care or get the usual oncology care plus a palliative care specialist who discussed this thing that we do not want to discuss. The ones who had that discussion ended up stopping chemotherapy sooner. They ended up choosing hospice earlier. They had less suffering at the end of life. And, they lived 25% longer.⁵

In the spring of 2015, the IHI, in conjunction with The Conversation Project (Table 1), published a white paper entitled “*Conversation Ready: A Framework for Improving End-of-Life Care*.”⁶ The article describes a detailed framework, built on 5 core principles to help organizations begin the process of becoming *conversation ready* (Table 2). The article also provides examples of changes tested by organizations and suggested measures to guide staff to become ready to receive, record, and respect the wishes of all patients.

The work of committed professionals and recent political events aligned health care providers in a new direction—with new insights, guided by research, patient stories, and new tools to begin this work. The Conversation Project provides a starter kit (adult and pediatric), guidelines for Death Over Dinner gatherings, and a framework to help organizations prepare to be “conversation ready.” Most recently, IHI launched a Community Resource Center geared toward sharing best practices for engaging people where they work, live, and pray.

TABLE 1 A Short History: The Conversation Project

The Conversation Project began in 2010, when Ellen Goodman, a noted writer convened a group of concerned media, clergy, and medical professionals to share stories of “good deaths” and “bad deaths” within their own circle of loved ones. Their grassroots public campaign used traditional and new media to encourage people to talk about their wishes for end-of-life care. The movement began to change our culture, as people responded to television events, Internet groups, and new finding about this topic. In 2011, The Conversation Project began its collaboration with the Institute for Healthcare Improvement (IHI). IHI is a not-for-profit organization that helps lead improvement of health and health care throughout the world.

Read more at <http://theconversationproject.org/about/>.

TABLE 2 The 5 Conversation Ready Principles Providing a Framework for Teams Working to Prepare Organization to Become “Conversation Ready”

- 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 care 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 fully understand the benefits and challenges.
 - Connect** in a manner that is culturally and individually respectful of each patient.
- The fifth, and perhaps most important, principle encompasses the other 4 principles because they all need to be conducted through this lens.⁶

These tools and the growing body of evidence-based practice supporting these discussions and early palliative care options are a wonderful place for us to begin a discussion about what Dr Gawande tells us are the 2 unfixable we all must face: aging and dying.

Most remarkably, and to my delight, July 9, 2015, brought the most exciting news!

The Centers for Medicare & Medicaid Services released a proposal to cover provider-patient time for conversations about end-of-life care. Payment for doctors and nurse practitioners to discuss end-of-life care with US patients may become a reality under rules proposed in July 2015 by the Obama administration.⁷

Talks may include outlining the sorts of medical treatments patients desire or helping to fill out standard forms about how they should be cared for if they are unable to make decisions for themselves. The administration’s proposal says the discussions should occur in the context of medical treatment.⁷⁻¹⁰ The entire document may be accessed at <https://www.federalregister.gov/articles/2015/07/15/2015-16875/medicare-program-revisions-to-payment-policies-under-the-physician-fee-schedule-and-other-revisions>. This proposal—reimbursement for having these complex and sensitive conversations—is a game changer!

The work continues, and progress is certain. Extensive research continues to add evidence to the value in talking to families and individuals early, before they (we) are patients, understanding, of course, that it is a process that must continue, as things evolve and life cycles bring new experiences and circumstances. As they do, nurses and physicians will prepare to educate students and staff armed with evidence and new methods.

Recently, Dr Susan Block, a palliative care specialist in Boston, and her colleagues described palliative care as an emerging field with a growing evidence base. This work tells us that improvements in care for many patients could also

improve value in accountable care organizations by increasing high-quality care and decreasing costs for the sickest patients. This work calls for us to develop competence in palliative care and improve our systematic approach to difficult diagnosis and end-of-life care.¹¹

Strong evidence dating back to 2010 reported that among patients with metastatic non-small cell lung cancer early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival.¹² This evidence continues to grow. In 2009, a multicomponent, psychoeducational interventions (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) was conducted by advanced practice nurses consisting of 4 weekly educational sessions and monthly follow-up sessions until death or study completion (n = 161) versus usual care (n = 161). Compared with participants receiving usual oncology care, those receiving a nurse-led, palliative care-focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood, but did not have improvements in symptom intensity scores or reduced days in the hospital or intensive care unit (ICU) or emergency department visits.¹³ Recent randomized controlled trials and interprofessional research continue to support early palliative care and guide us toward having more conversations about patient and family wishes.^{14,15} Project ENABLE grew into series of studies that have shaped the development of palliative care services at Norris Cotton Cancer Center and Dartmouth Hitchcock Medical Center. The ENABLE I, ENABLE II, and ENABLE III studies serve to determine if this supportive care intervention program can (1) improve quality of life and mood in patients with cancer, (2) reduce symptoms and time in the hospital, and (3) determine whether the exact timing of beginning these services will have any effect on quality of care. Results of ENABLE III suggest that concurrent oncology palliative care should be initiated as early as possible to maximize benefit to caregivers.¹⁶

Clearly, to offer these options, we must talk about it early and advise patients about care choices early, guided by a discussion of patient and family wishes.

Efforts are well underway to help us learn and develop programs to do this effectively, using the guidance and tools from The Conversation Project, IOM report, and the ever expanding body of evidence about early conversations and care options.

Most recently, Milic et al led educational workshops and reflection sessions for staff in the ICUs to help them feel more comfortable in discussions of prognosis and goals of care. Eighty-two critical care nurses completed a workshop. Compared with before the workshop, after the workshop, nurses reported greater skill and confidence for 14 survey

items ($P < .001$), including assessing families' understanding of prognosis and goals of care, addressing families' emotional needs, and contributing to family meetings.¹⁷

In this issue of *Dimensions of Critical Care Nursing*, Jenko and colleagues present a pilot project to facilitate palliative care referrals in the ICU. The researchers remind us that palliative care in ICUs reduces costs and improves outcomes, yet is consistently underused. The findings suggest that the PPSv2 tool was well received by the bedside nurses and changed practice patterns with regard to facilitating palliative care services.¹⁸ *Dimensions of Critical Care Nursing* has published many articles about palliative care, such as Erickson's insightful review of nurses' bedside involvement for end-of-life care.¹⁹ We will continue to provide our readers with information and education on this timely topic, as will our nursing colleagues.

Central to this work is the role of the advanced practice nurse, especially in light of the proposed federal reimbursement! Advanced practice nurses are prepared and uniquely suited to honor the patients' wishes at all junctures of care. A recent symposium, *Palliative Care for Advanced Practice Nurses*, presented in the *AACN Advanced Critical Care Journal*, presents 5 articles that address evidence-based interventions for end-of-life care in the ICU, resolving communication challenges and discussing ethical challenges and the role of the advanced practice nurse in improving discussions with patients and families.²⁰ This remarkable collection of work applies the goals of palliative care to the core competencies of advanced practice. Editors Buonocore and Wiegand bring the work of this national movement into the ICU and through all transitions in care with an understanding that palliative care is both a philosophy and a highly organized system of care.²⁰ While geared to advanced practice nurses, it is a comprehensive resource for all health care providers.

To learn more about this progressive movement in more detail, you can refer to the documents listed in Table 3 and follow the links on the reference list.

TABLE 3 Tools, Guidelines, and Proposals to Guide Difficult Discussions About Health Care Choices

The Conversation Project

Dying in America: Dying in America Improving Quality and Honoring Individual Preferences Near the End of Life

Being Mortal: Medicine and What Matters in the End

"Conversation Ready": A Framework for Improving End-of-Life Care. IHI White Paper

Centers for Medicare & Medicaid Services (CMS), HHS. Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016. 42 CFR Parts 405, 410, 411, 414, 425, 495[CMS-1631-P]RIN 0938-AS40

Continued research, practice guidelines, and expert opinion will continue to inform us and teach us how to talk about these issues. Ultimately, it is our bedside practice that will define our commitment to asking patients what matters to them. Only then will we understand their hopes, fears, and family concerns.

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