Consider the Conversation: How Do We Want it to End?

By Lisa Yarkony
We need to talk about how we want our lives to end. It’s important to have that conversation, urged Ellen Goodman, Pulitzer Prize-winning columnist for the Boston Globe. “My mom gets paid for telling people what she thinks,” said her 44-year-old daughter Katie. But Goodman didn’t know what to think when her own mother neared the end. She traced her recent campaign, the Conversation Project, to her role as “designated daughter” for her mother, who died nearly six years ago at age 92. “She had dementia and was no longer able to decide what she wanted for lunch, let alone medical decisions,” Goodman recalled. Yet once they had talked about everything from making cheese cake to making choices in life and family values. So why didn’t they have that talk? Goodman still wonders. And why didn’t they do it before it was too late?

“My mom,” Goodman recalled, “was one of those people who could talk about your problems until you were bored with them. We talked about everything except one thing: how she wanted to live at the end of her life. Once or twice, when we heard about a relative or friend who was comatose or on a feeding tube, she would say, ‘If I’m like that, pull the plug.’ But of course when the time came there was no plug,” leaving Goodman to make hard choices toward the end. “The last thing my mom would have wanted was to force me into such bewildering, painful uncertainty about her life and death. I realized only after her death how much easier it would have been if I heard her voice in my ear as these decisions had to be made. If only we had talked about it,” Goodman said. And after talking with friends and colleagues, she learned they had similar regrets. Together they founded the Conversation Project to “get people’s end-of-life wishes expressed and respected.”

Care that reflects patients’ goals comes when doctors, patients, and families join in making the best possible choice. A number of analysts and organizations, including the Medicare Payment Advisory Commission (MedPAC), have supported shared decision making, a process aimed at giving patients the facts and finding out what patients want. “Studies have consistently shown that decision aids, used with counseling, increase patients’ knowledge, give them a more realistic perception of treatment outcomes, increase the proportion of patients who are active in decision making, and improve agreements between patient values and the options they choose,” said MedPAC staffer Joan Sokolosky. Many patients will choose hospice once they realize treatment can’t cure them and will only hurt the quality of their remaining time.

When patients don’t know the limits of treatment, their consent to undergo it is not truly informed. But too often, this is the case according to a recent national study of nearly 1,200 patients with advanced lung or colon cancer. Overall, 69 percent of those with stage 4 lung cancer and 81 percent of those with stage 4 colon cancer failed to understand that “chemotherapy is not at all likely to cure their cancer,” said Dr. Jane Weeks from the Dana-Farber Cancer Institute in Boston. She also warned that this misunderstanding may stop them from making a wiser choice. “If you think chemotherapy is going to cure you, you’re less open to end-of-life discussions,” Weeks said, and you’ll delay the comfort care of hospice. When patients spend only a few days or weeks in hospice, caretakers don’t have enough time to get to know them and their families and offer the benefits hospice can provide.

What can make a huge difference is how often doctors discuss options with patients, said Dr. Thomas Smith, an oncologist and director of palliative care at Johns Hopkins Sidney Comprehensive Cancer Center. He has advised doctors to master the conversation known as “ask, tell, ask,” which consists of asking patients what they want to know about their prognosis, telling them what they want to know, and then asking, “What do you now understand about your situation?” Among the questions doctors should ask are “How much would you like to know about your cancer? What do you know about your cancer? Who would you like to include in discussions about your care? Would you like me to write down the important points? What is important to you? What are you hoping for?” And rather than having this conversation once, “it should be repeated at every transition point,” Smith said. Sadly, it often doesn’t take place at all, and doctors are largely to blame.

Patients want doctors to talk to them about end-of-life issues, but doctors seem to avoid the topic, according to a study recently published in JAMA Internal Medicine. ACCEPT, an ongoing project that examines care for ill, elderly patients in 12 acute care hospitals across Canada, has revealed barriers to end-of-life discussions between doctors and patients, with the result that many patients get treatments they don’t want or need. “Although most elderly patients prefer only comfort measures at the end of life, life-sustaining technologies are increasingly being used in the final stages of life,” said Dr. Daren Heyland, a principal investigator in ACCEPT. “It’s clear that there’s a communication problem between doctors, patients, and their families.”

Dr. Heyland’s contention is based on an in-person questionnaire given to 278 elderly patients and 225 of their family members. The results showed that the patients’ correct preferences for end-of-life care showed up only 30 percent of the time. For example, 28 percent of the patients stated a preference for “comfort care” — no life-sustaining treatments — but this was documented in only 4 percent of their charts. Many of the patients felt that information to determine their preferences for
end-of-life treatments was either lacking or unclear. “I didn’t know what he (the MD) was saying when asking me in the ER … Do I want CPR?” one patient recalled. “He asked with no explanation. I said sure if it works. He put down YES on the form but then told me it probably wouldn’t work and I would have brain function problems. Good God! I don’t want that! Give me the information first — then ask the questions.” “I don’t have enough information about his condition, what to expect and how long he has,” a family member moaned. “I am alone in all this decision making and feeling overwhelmed.”

Nearly half the patients had tried to spare their loved ones this dilemma by completing advance care plans and over 73 percent had formally designated a substitute decision maker. Yet only 30 percent had told their physician about it, another missed chance for productive talks, Heyland explained. “We know a significant number of ill, older people are already talking about their future health care decisions,” he said. “But they are waiting for their doctor to engage in that conversation with them. And the conversation needs to be clear, so that patients and family members can make an informed decision. We need to figure out how to get that conversation started.”

If it did, patients would suffer less and Medicare would cut costs because heroic, lifesaving measures are expensive.

Yet all the financial incentives in fee-for-service Medicare are aligned to induce more hospitalizations, more ICU care, and late hospice referrals. As we try to reform our health care system to provide patient-centered care, we need to focus on paying for quality rather than just more days in the ICU, especially if they don’t save lives. Yet during the debate over health care reform, a proposal to pay doctors for advance care planning was wiped from the legislation based on the argument that promoting shared decision making was akin to creating a “death panel.” Flaming rhetoric about euthanasia and killing grandma missed the point of this important provision. The goal was to encourage individuals and their families and doctors to think and talk about end-of-life options and wishes while they’re healthy, clear-headed, and not in the midst of a medical crisis.

Research into end-of-life care supports this approach, UCLA researchers wrote in *JAMA Surgery* this March. Patient-centered end-of-life care — ensuring that a dying person’s wishes are known and followed — results in happier, less depressed patients who live longer, the researchers noted in their paper. “Unfortunately, the opposite is usually what happens,” said Dr. Robert Bergman, an author of the *JAMA* paper. “Patients come in with incurable diseases, and there’s no discussion of prognosis and goals of care. Then a lot of very aggressive treatments can occur, due to inertia — patients are placed in an intensive care unit with oxygen and feeding tubes, and that’s not always in line with their goals.” To change this, lawmakers should revisit the issue of advance care planning and medical residents should be educated about patient-centered care, Bergman urged. “Better care in life’s final stages should and can be led by physicians who have accepted the mission of skillfully — and thoughtfully — caring for patients at every step of life’s journey.”

But it’s not easy for doctors to deliver dying words and counsel patients on hospice, said Dr. David Casarett, chief medical officer of the University of Pennsylvania Health System’s hospice program. “About once a year, a patient or family member will jump up and just walk out of the room when I mention hospice,” he recalled. “They will say, ‘We came to Penn for the best possible treatment. You were supposed to save Dad’s life and now you’re giving up on him. How dare you do that to my father!’” And even though such harsh reactions may be the exception, Casarett says they are enough to make many doctors nervous about bringing up hospice. “Physicians don’t want to cause that sort of distress,” he explained. “We’re basically nice people. We don’t want to walk in and start a conversation that will make a person start crying.”

Besides, many doctors haven’t been adequately trained in end-of-life care, said bioethicist Myra Christopher, and she’s sympathetic to their plight. “My heart really goes out to health care professionals who are being asked to do their work in a new way because historically their job has been to prolong life,” she said. “Most people avoid doing things that they don’t do well. Most of our doctors now have been socialized that death is a failure.” And their fears prevent them from starting talks about end-of-life planning, said Dr. Elizabeth Fine, professor in the Center for Geriatrics at the University Hospitals Case Medical Center in Cleveland. “I know there are physicians who feel that if they offer comfort as a priority or palliative care or
hospice that they’re giving up on the patient,” Fine said, “and they’ve failed in treating their disease. They won’t say that, I think. What they’ll say is, ‘I’ll be ruining their hope.’”

Physicians who do broach end-of-life issues tend to focus more on medical details than emotional issues, according to research that Fine published three years ago in the *Journal of Palliative Medicine*. Her article reviewed 20 studies involving end-of-life conversation and found several recurring themes. According to direct observers, doctors were more likely to talk about medical or technical issues than emotional concerns, though patients and families were eager to raise them. Doctors also tended to worry about the time involved, and they tended to dominate the conversation. So doctors, according to Fine’s recommendations, should seek training to improve their communication skills, speak less, and listen more to patients.

Now more patients are making their voices heard because of efforts to promote end-of-life talks, despite the time, effort — and sometimes tears — involved. “These aren’t quick conversations,” said Dr. Charles Cutler, a general internist in Norristown, Pennsylvania. “Don’t expect quick decisions,” he advised his colleagues. “Don’t even try that because if it hasn’t been thought through by the patient and the family then they’ll have second thoughts and buyer’s remorse and all that. You want to have a thorough conversation spread out over a long enough period of time so they feel comfortable with it. If the family’s not ready, or the patient’s not ready, it doesn’t help to try and convince them.” Granted, “hospice is the gold standard of end-of-life care for most people,” said Dr. Susan Block, professor of psychiatry and medicine at Harvard Medical School. “Yet for most patients, that first conversation about hospice is the first time anyone has told them that their disease wasn’t going well. It’s just too much to take in,” she acknowledged. “We want people to be prepared for the first hospice conversation before it’s too late.”

And there are resources to improve doctor-patient communication about end-of-life care. The National Cancer Institute’s website has a fact sheet that describes the rewards and challenges that come with planning end-of-life care. Researchers in California have launched a website, PREPARE, to help patients identify their priorities, communicate them with their families, friends, and physicians and make informed medical decisions. This communication should be two-way, according to the American Society of Clinical Oncology (ASCO), so it has recommended steps to ensure that physicians bring up all the options soon after a patient’s diagnosis. “While improving
survival is the oncologist’s primary goal, helping individuals live their final days in comfort and dignity is one of the most important responsibilities of our profession,” said ASCO President George W. Sledge, Jr., MD. “Patients have a right to make informed choices about their care. Oncologists must lead the way in discussing the full range of curative and palliative therapies to ensure patients’ wishes are honored.”

This is also the goal of two endeavors to reach patients and doctors across the country. National Healthcare Decisions Day in April is a collaborative effort of national, state, and community organizations to increase public awareness of advance care planning, spread knowledge of resources to help people make health decisions, and encourage health care providers to honor their patients’ end-of-life decisions. Physicians can also play a valuable role in guiding them to the best decisions, according to ABIM Foundation, which has awarded grants to 21 health care organizations across the country as part of its Choosing Wisely campaign. Choosing Wisely is an effort to help physicians and patients think and talk about medical tests and procedures that may be unnecessary and in some cases can cause harm. “Physicians say they sometimes have difficulty saying no to requests from patients, even when they know a particular test or treatment is unnecessary,” said Dr. Christine K. Cassel, ABIM president and CEO. “Through the work of these grantees, we’ll be able to help physicians in local communities across the country be better prepared to engage in conversations with their patients about the care they truly need.”

Even with the best intentions, there are no easy answers, according to Consider the Conversation. This must-see documentary looks at how Americans live at the end of their lives, based on interviews with patients, family members, doctors, nurses, social workers, and clergy from around the country. Their experienced voices tell us that communication and preparation are the keys to preventing unneeded suffering at life’s end. Their combined message has reached thousands of viewers, most of whom have left the theater blown away and even in tears. “Sure, it’s about a tough subject. It’s about a taboo subject,” said Terry Kaldhusdal, a fourth-grade teacher who co-produced the film with hospice educator Michael Bernhagen. “But it is really about how you want to live your life,” Kaldhusdal explained. “It’s a human issue. It’s about a conversation” — one that Ellen Goodman still wishes she’d had with her mom.

Since co-founding the Conversation Project she’s seen how hard it is get people talking about dying. “Elderly parents and their children enter into a conspiracy of silence,” Goodman explained. “Parents don’t want to worry their children. Children are reluctant to bring up a subject so intimate and fraught; some worry their parents will think they’re expecting or waiting for them to die. We often comfort ourselves with the notion that doctors are ‘in charge’ and will make the right decisions. And we all think it’s too soon to speak of death until it’s too late,” Goodman said.

She doesn’t want to wait too long, so last year she and her daughter recorded their own dialogue about Mom’s end-of-life wishes. “My biggest fear,” Goodman told Katie “is that there would come a time when I wouldn’t know the people I love.” “So what happens then?” Katie asked. “I’m not going to pull some plug while no one’s looking.” “No plugs,” Goodman agreed. “But I want you to have the courage to tell the doctors, ‘No more.’ No more chemo, feeding tubes — nothing that extends my body’s life after I’m not me. Choose less treatment, choose less pain, choose dying at home with all of you.” “Got it,” Katie shot back. “Whatever you decide, it’ll be okay. I know you’ll do the best you can. If you dare to feel guilty, I will come back to haunt you,” Goodman joked. But she’s dead serious about getting us to consider the conversation. “No one wants to bring up dying,” she said, “but talking with your loved ones about the final stage — theirs and your own — is essential.”

We all need to talk about how we want to die.

About the Author: Lisa Yarkony, PhD, is the managing editor of CARING Magazine. She has expertise in health systems both past and present. She can be reached at lisa@nahc.org.
REFERENCES


3 Ibid.


7 Ibid.


9 Ibid.


15 Ibid.


18 “Website aims to help patients make difficult medical decisions,” iHealthBeat, 7 January 2013, https://www.prepareforyourcare.org/.


