The JAMA Forum

Conversations About How We Die

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Earlier this year, neurologist and writer Oliver Sacks disclosed in an eloquent op-ed (http://nyti.ms/17hS3Eo) in the New York Times that an ocular melanoma treated 9 years earlier had now metastasized to his liver. Sacks wrote that the diagnosis gave him a new perspective: “This does not mean I am finished with life. On the contrary, I feel intensely alive, and I want and hope in the time that remains to deepen my friendships, to say farewell to those I love, to write more, to travel if I have the strength, to achieve new levels of understanding and insight.”

In a nation averse to talk about dying, this was a radical act. But Sacks is far from alone. Nurse Amy Berman (http://bit.ly/1BEGp0R) has been writing about her decision not to pursue aggressive treatment for incurable inflammatory breast cancer. Berman, who is the senior program officer for the John A. Hartford Foundation, has been a prolific advocate of patients’ rights to make informed choices about their care. Lisa Adams (http://nyti.ms/lbJiCuE), who died in early March, used social media to write about her metastatic breast cancer. Adams addressed the full range of emotions that can accompany a life with cancer and challenged her readers to move beyond pink ribbons. Atul Gawande’s Being Mortal (http://bit.ly/1vRJUHw) encourages health care providers to recognize the limits of medicine’s curative approach to all illness. And 29-year-old Brittany Maynard captured the nation’s attention last year with a video (http://bit.ly/ZcyyCB) explaining her decision to die on her own terms after suffering uncontrolable seizures caused by glioblastoma.

Institute of Medicine Report

For several years I became increasingly concerned that the political discussions (http://bit.ly/1NurFPo) surrounding health reform in 2009 had shut down important public conversations about how we die. Especially insidious was the “death panel” rhetoric that emerged from the idea that Medicare should pay clinicians to have voluntary conversations every 5 years, or more often if needed, with patients about their end-of-life wishes.

Now, a 2014 Institute of Medicine (IOM) report, Dying in America: Improving Quality and Honoring Preferences Near the End of Life (http://bit.ly/1p1AGDQ), has called for an increase in public conversations about improving care of those who are dying, countering the fallout (http://bit.ly/1NurFPo) from the “death panel” business. It calls for (http://bit.ly/lyr6h1G) making “a person-centered, family-oriented approach that honors individual preferences and promotes quality of life through the end of life . . . a national priority.”

Conversations are the key to achieving this aim in several ways.

First, to “encourage” informed choice based on the needs and values of individuals,” the IOM report recommends that government, religious, and health care leaders, among others, engage in public education campaigns about evidence-based care for
Changing how we die in America will mean changing how we live. It demands a chorus of conversations. Many health care professionals are reluctant to talk (http://1.usa.gov/1CyChE) to patients and families about preparing for the end of life, and research (http://1.usa.gov/1JFRTZ) has shown how this reluctance affects care. The report calls for normalizing these discussions by starting them at “some key maturation point”—for example, when a young person goes to university or into the military or must consider organ donation when getting a first driver’s license. But people don’t have to wait for a health professional to initiate the conversation. Let’s Have Dinner and Talk About Death (http://bit.ly/IxMjPDJ) is just one initiative that provides people with a structure for having conversations about dying with the people of their choosing—whether children, parents, spouses or friends—when they are still well. Founder Michael Hebb suggests (http://bit.ly/1BJskHF) that “The dinner table is the most forgiving place to have this kind of conversation...it’s liberating...and hopefully leaves us more prepared for a conversation with our doctor...”

Third, such conversations won’t happen if health care professionals don’t know how to have them. The report recommends that health professionals’ training in discussing end-of-life issues be tied in with their requirements for relicensure and certification.

Fourth, the report calls for the development of measurable, evidence-based standards for advanced care planning and clinician-patient communication to support this planning. Payers need to link payment to transparent quality measures that reflect informed choices by patients.

Finally, none of this will evolve if we don’t provide and pay for care aligned with the values, preferences, and goals of patients who want to die at home, with their families to care for them. That will mean paying for health care professionals to have periodic conversations with patients about advance directives. It may require legislation, especially for refocusing Medicare and Medicaid rules and payments, including for hospice care, to offer patients a range of comprehensive services that can be aligned with their needs and preferences.

Redesigning Programs
We can hope that people at the Centers for Medicare & Medicaid Services (CMS) and in the relevant Congressional committees have read this report, with a mind toward redesigning federal programs to reduce the gap between the services they pay for and what patients and families actually want and need. The report calls for government to push private payers to link payment with end-of-life options that patients can choose. Aetna has already expanded (http://bit.ly/19AFL4w) its coverage of options for patients in the last year of life.

Improving end-of-life care for patients and families can also reduce costs, as the report makes clear, as patients opt for fewer aggressive treatments and avail themselves of palliative and hospice care. Of course, linking lowered costs with improved end-of-life care risks reviving the “death panel” rhetoric. But it’s an important point we shouldn’t keep hidden.

The health care system must not fail Sacks, Berman, and the many others revealing to us what it’s like to face the end of life.

“It is up to me now to choose how to live out the months that remain to me,” Sacks wrote. Changing how we die in America will mean changing how we live. It demands a chorus of conversations. No more silence, please. •

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