Should We Practice What We Profess? Care near the End of Life

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Physicians should be in a better position than people without medical training to judge the likely value of health care services available near the end of life. Yet several studies have revealed a disconnect between the way physicians themselves wish to die and the way the patients they care for do in fact die.

A 1998 survey of participants in the Precursors Study, which enrolled 999 physicians who graduated from Johns Hopkins School of Medicine between 1948 and 1964, revealed that 70% had had a conversation with their own personal physician about end-of-life care. But 64% had an advance directive that they’d discussed with their spouse or family, and more than 80% indicated that they would choose to receive pain medication but would refuse life-sustaining medical treatments at the end of life.1 Similar preferences were expressed in a 2013 survey of 1147 younger academic physicians (a group that was more diverse and included more women): 88.3% indicated that they would forgo high-intensity end-of-life treatment.2

Although physicians ought not assume that their views about dying should apply to others, public surveys and research studies have shown that 80% of Americans, like the large majority

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Summary of IOM Committee Recommendations.*

Delivery of care
Government health insurers and care delivery programs, as well as private health insurers, should cover comprehensive care, including palliative care and hospice care for persons with advanced serious illness who are nearing the end of life.

Clinician–patient communication and advance care planning
Professional societies and other organizations should develop standards for clinician–patient communication and advance care planning that are measurable, actionable, and evidence-based. Payers and delivery organizations should adopt these standards and their supporting processes and integrate them into assessments, care plans, and the reporting of health care quality.

Professional education and development
Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish appropriate training, certification, and licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for patients with advanced serious illness who are nearing the end of life.

Policies and payment systems
Federal, state, and private insurance and health care delivery programs should integrate the financing of medical and social services to support the provision of high-quality care consistent with patients’ values, goals, and informed preferences. Insofar as additional legislation is necessary to implement this recommendation, the administration should seek and Congress should enact such legislation. The federal government should require public reporting on quality measures, outcomes, and costs and encourage private payers and delivery systems to do the same.

Public education and engagement
Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information to encourage advance care planning and informed choice based on individuals’ needs and values.

* The full report is available at www.iom.edu/endoflife.

Teno et al. noted that the rate of acute care hospitalization decreased from 32.6% in 2000 to 24.6% in 2009 but that use of intensive care in the last month of life increased from 24.3% to 29.2%. Although hospice use increased during this period, 28.4% of the decedents studied had used hospice for 3 days or less in 2009.

Complex social, cultural, economic, geographic, and health system factors and impediments contribute to this discordance between how doctors treat their patients and how they themselves (and the majority of surveyed Americans) wish to be cared for at the end of life. We are experiencing the greatest demographic shift in U.S. history. According to current projections, by 2030, 20% of Americans will be more than 65 years old. Cultural diversity is also increasing, as is the percentage of people with one or more chronic illnesses. It is therefore imperative that the medical community listen to patients and recognize that their end-of-life preferences may change over time, especially as longevity increases. The goal should be to help people receive care in keeping with their personal preferences as they near the end of life.

In Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life, an Institute of Medicine (IOM) committee (which we cochaired) concluded that the U.S. health care system is poorly designed to meet the needs of patients and their families at the end of life and that major changes are needed. We need to begin by fostering patients’ ability to take control of their quality of life throughout their life and to choose the care they desire near the end of life. The committee of surveyed physicians, say they’d like to die at home and avoid high-intensity care and hospitalization. Yet their wishes are too frequently overridden by the physicians caring for them, who take more medical interventions than patients desire. Physicians also sometimes find themselves responding to the wishes and demands of patients’ families who want more medical therapy than medical providers believe is indicated or beneficial. In a study examining the care of more than 848,000 people who had died in 2000, 2005, or 2009 while covered by fee-for-service Medicare,
recognized that these goals could be achieved only by making major changes to the education, training, and practice of health care professionals, as well as changes in health care policy and payment systems. Simultaneously, individual and public education would have to be radically reformed to reshape expectations and allow patients and clinicians to have meaningful discussions about end-of-life planning (see box).

The IOM committee concluded that “federal, state, and private insurance and health care delivery programs should integrate the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life.” More specifically, the committee recommended that insofar as additional legislation is required to allow for such financing, relevant laws should be enacted (e.g., authorization of payments for services delivered in ambulatory or home settings rather than only in inpatient settings) and that the federal government should “require public reporting on quality measures, outcomes, and costs regarding care near the end of life . . . for programs it funds or administers (e.g., Medicare, Medicaid, the Department of Veterans Affairs)” and encourage other U.S. payment and delivery systems to follow suit. We believe that physicians can and should work with their professional organizations to advocate for these changes — but rather than waiting for new legislation, they can take action now, in part by setting aside time to encourage patients to express their preferences regarding end-of-life care.

Physician practices can also organize their clinical services so as to provide seamless, high-quality, patient- and family-centric care that is consistently available to their patients, especially those who have advanced serious illness or are nearing the end of life. Even by simply providing patients with a consistent and accessible place to call when they need help, physicians can avert unnecessary trips to the emergency department or another acute care setting where patients’ individual preferences may not be known or honored. Becoming more accessible in this way improves the quality of care and should reduce unnecessary utilization of expensive medical treatments.

Physicians can also work to ensure that their patients have access — in all care settings — to skilled palliative care or, when appropriate, hospice care. We believe that basic palliative care skills should be part of the knowledge base of all physicians caring for people with advanced serious illness or near the end of life. Physicians can also seek out collaboration, whenever possible, with skilled palliative care specialists, whether doctors, nurses, social workers, or clergypersons, to ensure the best possible care of their patients. It has been demonstrated that when palliative care is combined with active treatment for patients with advanced cancer, the quality and duration of life are enhanced. All this care should be coordinated, and handoffs should be avoided at critical junctures for patients, such as when they first encounter a chronic illness or a life-threatening disease.

Ideally, physicians would initiate discussions about advance directives with their patients at key milestones throughout their lives — perhaps when they get a driver’s license, get married, begin a new job, relocate, or become eligible for Medicare — not just when advanced illness or death is imminent. Many physicians need to learn how to conduct these conversations respectfully and successfully. Physicians can then make their patients’ preferences known to all members of the health care team. Physicians should be compensated for the time required to have these discussions — a change they can prod the government and other payers to make.

Changing the culture in these ways will require intervention at all stages of physicians’ education. Physician educators can develop new models of teaching (including the use of simulation) for students, residents, and fellows. But physicians can also learn and teach about compassionate patient care in their practice settings and communities. They can then contribute to public dialogues about end-of-life issues in their communities and religious groups — working especially to help to dispel misinformation.

Physicians’ experiences with medical care and dying patients have helped crystallize their desires for their own end-of-life experiences. As Dying in America makes clear, physicians should now practice what they profess, to ensure that their patients have the same options that they themselves, and a majority of Americans, would choose and that they honor patients’ preferences at the end of life.

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Finding the Right Words at the Right Time—High-Value Advance Care Planning
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When Ms. C. died, I was sad but not surprised. I had met her 4 years earlier, when I was an intern and she was the first patient who identified me as “my doctor.” She did so enthusiastically, asking the inpatient medical teams who frequently cared for her to run every decision by me. As a trainee, and given her complex needs, I found those requests both absurd and overwhelming. By 65 years of age, Ms. C., a lifelong smoker, had coronary artery disease, atrial fibrillation, diabetes, and chronic obstructive pulmonary disease (COPD) complicated by pulmonary hypertension. During the time I knew her, she was hospitalized at least every 3 months for complications of one or another of her chronic conditions. The only thing she hated more than the hospital was the panic induced by uncontrolled dyspnea, chest pain, or palpitations—the panic that led her to dial 911. When she came into the clinic for follow-up, she’d tell me that she never wanted to go back. I would check to make sure she understood her medication changes. She would ask about my family. I would plead with her to quit smoking. A gregarious Latina, she always shouted “I love you” as I walked out of the room.

I remember when Ms. C.’s cardiologist, who was as close to her as I was, told me he was concerned that she might not live another year: her arrhythmia had become more difficult to control. She had no advance directive. He suggested that I speak with her about it, and I said I’d try to find a good time. I never did.

Some months later, as a newly appointed attending, I returned from a vacation to an e-mail informing me of Ms. C.’s death. She had died in the intensive care unit after an unsuccessful attempt at cardiopulmonary resuscitation. I’m pretty sure that’s not what she would have wanted, but I couldn’t say for certain. I stared at my computer screen, feeling the leaden weight of a missed opportunity and a sense of profound disappointment in myself. I felt that I had failed one of my first and favorite patients.

Since becoming a palliative care doctor some years later, I’ve thought many times about Ms. C. and the consequences of my own and others’ inaction. And these missed opportunities have become a topic of national conversation. Last September, the Institute of Medicine (IOM) released a report entitled Dying in America, in which it recommends measures to improve end-of-life care through, among other strategies, better advance care planning (ACP). Specifically, it recommends the development of “standards for clinician–patient communication and advance care planning that are measurable, actionable, and evidence based” and that these standards be tied by payers and professional societies to “reimbursement, licensing, and credentialing” (see Perspective article by Pizzo and Walker, pages 595–598).

If promoting ACP discussions were as simple as asking or paying physicians to have them, Dying in America might not have been necessary. These discussions are difficult, and for multiple reasons: perceived difficulty of prognostication, uncertainty about how best to communicate with patients and families with diverse communication needs, and inadequate time to have them—not to mention the troubling emotions that talk of death raises for both patients and physicians. During our medical education, discussions of end-of-life care receive minimal, if any, attention.

In response to deficiencies in physician communication about end-of-life care preferences, policymakers, patient advocates, and payers have endeavored to move ACP out of physicians’ hands, from the clinic to the telephone...