

Talking It Out: Helping Our Patients Live Better While Dying

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Although dying is an inevitable part of the life cycle, there has been extensive political debate over end-of-life care. Participating in end-of-life care conversations can be emotionally challenging for everyone involved. Messages about serious or terminal illnesses can be very hard for patients and their families to hear, and physicians frequently struggle with the burden of delivering these messages. Still, evidence shows that conversations about end-of-life care options between physicians and patients can improve the quality of life of dying patients and help to relieve the emotional burden on surviving loved ones.

Legislation to support these discussions by consistently reimbursing physicians for their time spent performing this service has been blocked on multiple occasions. More research on how to improve end-of-life care will enable health care providers to optimize treatment of their patients. Overcoming political divides to support end-of-life care conversations is needed to promote care that is consistent with patients' values and needs and is a key step in encouraging better quality of life for dying patients.

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On the day before Thanksgiving, a 45-year-old mother, Maria, sits anxiously in her oncologist's office. She learns that the aggressive form of breast cancer that she has battled for the past 4 years has now metastasized to her brain and spine. Despite several years of treatments and many good visits with her medical team, her death now confronts her at the speed of a head-on collision.

Within a short time, Maria, together with her family, must decide how to proceed. She can choose only comfort care. Or, in the hopes of living at least through the holidays, she can opt for more aggressive types of chemotherapy. In the moment of hearing her prognosis, such issues as the uncompromising adverse effects of these medications, the inconclusive evidence that supports their benefit, and the cost of these treatments seem less important than the question of how she confronts her own death.

THE POLITICS OF END-OF-LIFE HEALTH CARE

During the health care reform process in 2009, legislation was introduced to reimburse physicians for time spent providing Medicare patients with voluntary counseling on end-of-life care options. This legislation would have reimbursed physicians for their time spent counseling patients on how to prepare advance directives to outline the type of care that they would want when faced with serious illness. This legislation also would have helped physicians spend more time discussing such options as palliative care, which aims to relieve suffering and improve quality of life for patients regardless of what other treatments the patients are receiving or how long they might live. If hospice care is consistent with patients' desires, physicians also educate patients about this option, which provides comfort and support to patients in the last stages of their illness and to their families (1).

Some opponents who hoped to block the larger health care reform process were successful in exploiting many people's fears of the dying process. An Institute of Medicine report on end-of-life care characterized some of these anx-

ieties, by noting that "people have come both to fear a technologically over-treated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress" (2). Opponents of end-of-life counseling legislation and the larger reform process cited that passing the end-of-life counseling legislation would lead to governmental rationing of health care services at the end of life and thus propagated the myth that a "death panel," rather than patients themselves, would determine the type of care that patients would receive near the end of their lives. As a result, the 2009 end-of-life counseling provision was dropped from health care reform legislation.

At the end of 2010, a similar rule to reimburse physicians for end-of-life planning was approved through a small Medicare regulatory change. Proponents of end-of-life counseling legislation celebrated silently for fear that any infusion of politics would lead to reversal of this regulation (3). Just a few days later, as the new Congress was sworn in and heated debate on reversing health care reform seemed inevitable, this regulation was quickly reversed. In the midst of such political debates, the most important lesson—that clinicians should have better individualized conversations with their patients—is lost to the public.

COMPLICATED CONVERSATIONS FOR DIFFICULT DECISIONS

Many patients living with serious illnesses like Maria's will face the unavoidable moment when the disease reaches the final stages. Evidence shows that patients who have more discussions with their physicians about end-of-life care preferences are more likely to accept that their illnesses are terminal and that these patients are empowered by expressing their wishes. Nevertheless, many physicians do not know their patients' end-of-life care preferences (4, 5). Early discussion of options, such as palliative care and hospice, can help prepare patients, surrogate decision makers, and physicians to make the difficult choice when the moment does arrive (6). End-of-life care conversations also

have been shown to help reduce the emotional burden on surviving relatives (4).

Maria's experience of waiting to address challenging end-of-life treatment decisions only when the terminal stage of her disease approached is common (7). Because broaching end-of-life care discussions can be challenging for all parties involved, they are frequently deferred until the end stages of an illness. In a traditional 15- to 30-minute visit, a physician must review a patient's medical history, perform a physical examination, and make immediate treatment decisions; it is no wonder that these discussions often are neglected. When clinicians are prepared to discuss these issues, patients are coping with their diagnoses and often struggle to receive the message. Finally, physicians frequently receive little training in conveying these ominous messages and can experience burnout and compassion fatigue, which further complicate effective discussions (8).

Physicians have always played a key role in counseling their patients through different life stages. For example, health care providers offer prenatal counseling to expectant mothers and advise patients about preventing or managing cardiovascular disease and diabetes. These activities take time and, because they improve care, are reimbursed. Although we cannot remove the emotional experience from end-of-life care counseling, structural improvements, including reimbursing time spent on end-of-life care planning, can help physicians continue to perform their roles as counselors of health and illness throughout the stages of life.

TOOLS FOR TALKING

The high costs of health care add to the overheated rhetoric of the end-of-life care debate. Health care that is provided in the last year of life accounts for more than 25% of total Medicare costs (9). The worst aspect of these high expenditures is that they often do not improve quality of life. One report showed that patients with advanced-stage cancer who had end-of-life care conversations with their physicians incurred lower health care costs in their last week of life, a time when a disproportionate amount of costs currently accrue, than those of patients who did not have these conversations (10).

However, the purpose of end-of-life care conversations is not to steer patients away from choosing aggressive treatments, but to empower them with the information they need to make the decisions that are best for them. Mounting evidence suggests that we can use our resources more efficiently to achieve the result that everyone wants: better quality of life for dying patients (11).

Further research into improving the quality of care provided at the end of life is needed and will strengthen the abilities of clinicians to optimize care of dying patients. In addition to reimbursing providers for counseling on palliative care, advance directives, and hospice services, struc-

tural improvements should include more extensive palliative care and end-of-life care training for medical students and physicians. One recent survey of medical students showed that students exposed to more formalized and bedside end-of-life care curricula reported feeling better prepared to provide good end-of-life care than those without similar education (12).

Another organizational change to improve the quality of end-of-life care is the widespread adoption of such programs as the Physician Orders for Life-Sustaining Treatment (POLST) paradigm. Unlike a conventional advance directive, which is a legal document that can be prepared years before a patient is expected to die, a POLST form is a physician's order that is signed after the physician addresses predictable medical scenarios with a patient who is expected to die within the next few years. Once a patient has considered these scenarios, his or her preferences are documented as medical orders intended to guide health care providers to deliver care that is most consistent with the patient's values and wishes (13).

POLITICS NO MORE

Maria was my mother, and I have often thought about the way that she died. Faced with her difficult decision, she proceeded with additional chemotherapy treatments and survived for 4 months after her terminal condition was diagnosed. In retrospect, I cannot know how her quality of life would have differed if she had received only comfort measures, nor say that the decision to have more aggressive treatments was a bad one. Nevertheless, years later, I recall the conversation with her oncologist that helped to keep her out of the intensive care unit when it seemed like this step could prolong her life. Even while the oncologist was telling my mother and our family that she would not survive much longer, a brief and compassionate physician encounter gave us the hope of comfort through her last days.

I am sharing my mother's story to remind us that, because dying is a complex process, the decision of what type of care to proceed with is also often complicated. This choice is based on an individualized decision process shared among the patient, his or her family, and the physician. Such decisions should be made after patients have had the opportunity to discuss all options and should ideally occur over time through the various stages of an illness.

Physicians and health care providers, by continuing their long-standing roles as counselors, have an important opportunity to reframe how the public perceives end-of-life care issues. Critical steps in achieving this include assisting clinicians with structural improvements that improve the quality of end-of-life care and enacting a consistent mechanism to support the time spent having end-of-life conversations with their patients.

Evidence shows that discussions to determine the best individualized care for patients may help to ease some of the burden of the dying process. As Congress continues the

heated debate on the provisions of health care reform, one thing is clear: Achieving real reform requires addressing the entire span of life circumstances, including the end of life.

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