

Care at the End of Life

Care at the end of life has been receiving considerable attention of late, much of it in the popular press, especially the *New York Times*. At the end of August, the *Times* ran an article describing how coverage for end-of-life conversations is gaining ground with some private insurers, for Medicaid patients in some states, and, possibly, for Medicare patients if the Centers for Medicare and Medicaid Services approves a request from the American Medical Association. The A.M.A. creates billing codes for medical services and recently created codes for end-of-life conversations which were submitted to Medicare (Pam Belluck, “Coverage for End-of-Life Talks Gaining Ground,” August 30, 2014). A decision should come this fall. If positive, it will likely give impetus to additional private insurers to follow suit. Studies have shown that end-of-life conversations can make a difference in how people die.

Several articles appeared in September and October, most of a narrative nature—accounts of the dying experience of a relative or acquaintance—but with a lesson to be learned. One such account was titled “When It’s the Doctor Who Can’t Let Go” (Theresa Brown, September 7, 2014). The author concludes the piece this way: “Physicians also need to recognize that there are occasions when the patient’s fate is not, in the end, the doctor’s work. Every patient deserves care on his own terms, for each patient’s life, and death, is his own.” Writing from the opposite perspective, to

some degree, a physician whose father was active in the medical futility movement, writes that “physicians need to reclaim some of the turf they have ceded to patients and families.” He goes on to say that his father would have approved of the recommendations in the recent Institute of Medicine Report, “Dying in America,” but he also would have wanted more: “for doctors to be bolder and more courageous, to see their duty not simply as providing options but as making sure patients got the most appropriate care, even if that meant saying no to specific demands” (Barron H. Lerner, “When Medicine Is Futile,” September 19, 2014; see “Letters: Who Speaks for Dying Patients,” September 25, 2014).

Another account (Nina Bernstein, “Fighting to Honor a Father’s Last Wish: To Die at Home,” September 25, 2014) describes in some length how virtually every aspect of the health care system—hospitals, nursing homes, home health agencies, Medicare and Medicaid—conspired against the possibility of the author’s father’s dying at home as he so fervently wished. She observes that most of the medical spending was wasteful and could have been redirected to what would have been beneficial—social services and supports. Public money, she maintains, benefits health care businesses, but not necessarily patients.

This same point was made a week later in a *New York Times* editorial commenting on Ms. Bernstein’s experience. The editors write: “Two issues raised by this case seem particularly troubling. Virtually every

institution took actions that served its own needs, not the patient's. And there was no coordination between Medicare and Medicaid." They go on to mention the Institute of Medicine Report that calls "for an overhaul of how care is delivered near the end of life to eliminate the mismatch between what patients and families need and the services they can obtain."

Atul Gawande provides another personal account—"The Best Possible Day" (October 5, 2014), and also discusses what he learned from over 200 interviews he conducted in preparation for his latest book, *Being Mortal: Medicine and What Matters in the End*. He writes: "And among the many things I learned, here are the two most fundamental. First, in medicine and society, we have failed to recognize that people have priorities that they need us to serve besides just living longer. Second, the best way to learn those priorities is to ask about them. Hence the wide expert agreement that payment systems should enable health professionals to take sufficient time to have such discussions and tune care accordingly." What might some of these priorities be? He goes on to explain: "Medicine has forgotten how vital such matters are to people as they approach life's end. People want to share memories, pass on wisdoms and keepsakes, connect with loved ones, and to make some last contributions to the world. The moments are among life's most important, for both the dying and those left behind. And the way we in medicine deny people these moments, out

of obtuseness and neglect, should be cause for our unending shame."

Several of these accounts come in the wake of the Institute of Medicine's 500-page report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (September 2014) and even make reference to it. The report states that "broad improvements to end-of-life care are within reach" and it identifies not only specific areas for improvement but also concrete steps that can be taken to reach this goal.

Shortly after the IOM Report was released, Brittany Maynard, diagnosed with terminal brain cancer, announced in a CNN op-ed that she will end her own life on November 1 in order to avoid a long, debilitating, and painful dying. In an op-ed in the *New York Times* on October 11, 2014, columnist Ross Douthat, after referencing Maynard, asks "why, in a society where individualism seems to be carrying the day, is the right that Maynard intends to exercise still confined to just a handful of states? Why has assisted suicide's advance been slow, when on other social issues the landscape has shifted dramatically in a libertarian direction?" ("The Last Right: Why America Is Moving Slowly on Assisted Suicide"). Meanwhile, Compassion and Choices seems to be gearing up in California for another attempt to legalize physician-assisted suicide. While eschewing physician-assisted suicide and euthanasia, physician Ezekiel Emanuel writes in an article ("Why I Hope to Die

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at 75”) in *The Atlantic* that he wants to die at 75 in order to not experience the physical and mental diminishment and debilitation of old age.

At the other end of the spectrum is Judie Brown writing in a column on the Renew America website (“The Big Scare in Obamacare,” October 14, 2014) that Catholic health care’s Supportive Care Coalition is part of a coalition urging Congress to pass legislation to replace costly life-saving care for the ill with palliative care, all in an effort to save money. She writes: “[L]et’s just say that when the Supportive Care Coalition’s homepage tells everybody that it is the ‘voice of advocacy for palliative care,’ we can translate that into meaning that it is part of the effort to redefine pain management that moderates the pain for the ill and dying into terminal medication for cost-saving purposes. It’s euthanasia with a pretty face.”

The IOM Report and the various accounts noted above underscore the need for significant efforts to improve care at the end of life. While advances have been made over the years, there is clearly still a long way to go. The IOM Report offers something of a blueprint—a blueprint that needs to be embraced and implemented by a host of individuals from politicians to government agencies to health care organizations and health care professionals. Improving care at the end of life in order to reduce if not completely eliminate the types of experiences narrated in the above accounts is the responsibility of all. Without taking up this responsibility, change will not come or

will come much more slowly. Bringing about the needed improvements is a challenge in itself. It is only complicated by those who denigrate palliative as “euthanasia with a pretty face” or those who elevate the exercise of autonomy and control above so many other considerations.

R.H.