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PERSONAL HEALTH

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End-of-Life Issues Need to Be Addressed

By [JANE E. BRODY](#)

In all the discussion of [health care reform](#), there is one issue that has received short shrift but has the potential to save billions of dollars and untold suffering if it is effectively addressed. I'm talking about futile treatments at or near the end of life.

Even the most innocent suggestion — a provision in the House bill to reimburse doctors who discuss end-of-life options with patients and families — was attacked by two Republican congressmen as taking us on the path to “government-encouraged [euthanasia](#).”

Nothing could be further from the truth. This accusation, in a statement by Representatives [John A. Boehner](#) of Ohio and Thaddeus McCotter of Michigan, reveals a profound misunderstanding of how most people say they want to be treated when their chances for meaningful survival are nil. Yet few have put their wishes in writing or even discussed them with their next of kin, leaving doctors and families in the lurch when their lives hang in the balance.

‘A Death Prolonged’

Most measures taken when patients are terminally ill, including the use of feeding tubes, ventilators and [cardiopulmonary resuscitation](#), do nothing to prolong meaningful life. Rather, as Dr. Jeff Gordon put it in the title of his new book, they represent “A Death Prolonged.”

The book is a fictional account of situations that Dr. Gordon has commonly observed as a full-time doctor — a hospitalist — at the Grant Medical Center in Columbus, Ohio. In the introduction he writes: “Today’s high-tech medical care can sustain technical life — the beating heart — but utterly fails to restore real quality of life for many. There comes a point when physicians can prolong dying, but not provide quality living.”

In 2005, the Hastings Center, a research organization in Garrison, N.Y., that deals with ethical issues in health and medicine, produced a report called “Improving End of Life Care: Why Has It Been So Difficult?”

“Despite 30 years of litigation, laws and efforts by a range of groups to improve treatment for those near death,” the report’s summary says, “too many Americans still receive poor care at life’s end and are dying ‘bad’ deaths without adequate palliative care or dignity.”

Dr. Joanne Lynn, a geriatrician in the Community Health Administration of the Department of Health in Washington, D.C., noted in the report that the health care system in the United States had made it possible “to live for years ‘in the valley of the shadow of death.’ ” Unfortunately, she added, there are no strong industry interests to advocate for good care at the end of life.

Crucial Questions

As a hospitalist, Dr. Gordon has had many opportunities to observe the agonies of a bad death — one in which patients failed to leave adequate instructions for how they should be treated when therapy for their disease is no longer helping.

The questions are critical, even if some people find them difficult to contemplate. Should a feeding tube be installed when the patient can no longer be nourished by mouth? Should a ventilator be attached when breathing independently becomes difficult? If the patient has severe [dementia](#), should [antibiotics](#) be used if [pneumonia](#) develops? Should cardiopulmonary resuscitation be attempted if the heart stops beating?

Or should the patient receive just comfort care — treatment for pain, nausea, [anxiety](#), [depression](#) and other debilitating symptoms — and be allowed to die a natural death?

Only about one-third of Americans have completed any kind of advance directive to guide their families and physicians when they cannot speak for themselves. Of the advance directives that have been executed, many, if not most, are too vague to be truly useful.

Lacking guidance from patients and families, physicians who know better too often end up providing costly life support for the terminally ill even though there is no hope for an improved quality of life.

Furthermore, Dr. Gordon noted in an interview, most people, who are schooled primarily by TV dramas, vastly overestimate the chances of survival after resuscitation. While on television more than 60 percent survive after CPR, in real life only 5 to 10 percent of patients over 70 survive resuscitation in a hospital.

Even doctors commonly overestimate the success of CPR, Dr. Gordon said. Only a third know accurate survival rates.

Physicians also still commonly ignore the requests of patients or designated patient representatives to avoid high-tech life support. A friend was recently intimidated by a doctor who wanted to insert a feeding tube into her terminally ill father, who had suffered a stroke.

“I don’t believe in starving my patients,” the doctor said when she told him her father would not want such intervention. And so the feeding tube was inserted, and the patient, who requires 24-hour care, continues to make frequent trips to the hospital with infections and other complications.

As the Hasting Center report stated, “Physicians unwilling to give up and indifferent to patient desires are still with us.”

The system is not saving lives, Dr. Gordon says. “We’re torturing patients by prolonging their deaths. And the cost to society is astronomical.”

He cited a study published in The New England Journal of Medicine in 1993. It found that about 30 percent of Medicare dollars are spent during the last year of life, and half of that is spent during the last 60 days. In 2009 dollars, Dr. Gordon calculated, that amounts to \$70 billion a year, much of it spent on futile care that prolongs suffering.

Costs and Benefits

This “incredibly expensive end-of-life care” detracts from the health care system’s ability to finance preventive care, Dr. Charles A. Bush, the medical director of Richard M. Ross Heart Hospital at the [Ohio State University](#), told me.

In addition to their high cost, common life-prolonging interventions can result in a host of debilitating or costly complications, like repeated infections, mental deterioration, serious drug reactions and persistent pain and discomfort. That doesn’t even include the distress experienced by family members tending to loved ones hooked up to myriad tubes and devices.

Sometimes, out of guilt or misunderstanding, family members insist that “everything that can be done should be done” to keep their dying relatives alive as long as possible. But as the main character in Dr. Gordon’s book puts it, “I wish more people knew the misery of ‘everything.’ ”

Too many families equate the failure to provide life support with “killing” the patient, Dr. Gordon has found. But, he insists, doctors who eliminate high-tech interventions are not killing patients. Nor does he advocate physician-assisted [suicide](#).

Rather, he wrote: “We keep people comfortable and let nature take its course. Given the opportunity, most people would not choose a prolonged, painful death. Instead, they would choose a natural, dignified death.”

To help people make sound health care decisions and get the care they would want for themselves or their family members as life draws to a close, the National Institute on Aging has produced a [comprehensive 68-page booklet](#), “End-of-Life: Helping With Comfort and Care.” Individual free copies can be obtained through the institute’s Web site, www.nia.nih.gov, or by calling 800-222-2225.