

The Long (and Expensive) Good-Bye

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Executive Summary: The 2010 Affordable Care Act was designed (in part) to reduce the rising and unsustainable cost of healthcare while improving its quality. One area in which this value equation is vividly out of whack is end-of-life care. In the United States, a disproportionate percentage of healthcare costs are incurred over the last two years of life even as studies show that aggressive and expensive end-of-life treatments do not significantly extend life. They do, however, make what's left of someone's life worse. Furthermore, most Americans do not want aggressive end-of-life, hospital-based treatment, preferring to die at home, as comfortable as possible, surrounded by family and friends. A straightforward solution to this problem is advance care planning for end of life that creatively and compassionately involves providers and patients in a discussion that airs options and preferences. Employers and payers also can support advance care planning. Properly implemented, advance care planning that includes in-hospital and at-home hospice care and other palliative treatments can help all parties hit the sweet spot where costs go down as quality (of care and of life) improves.

What Nobody Wants

Nobody wants to die in a hospital intensive care unit (ICU), surrounded by beeping machines, flashing lights and hovering strangers, no matter how well-intentioned they may be. When asked, [more than 80 percent of patients say they wish to avoid hospitalization and intensive care](#) during the terminal phase of an illness, according to a recent Dartmouth Atlas of Health Care study. People want to die at home, surrounded by their family and friends, as comfortable as possible.

Why, then, [according to a 2013 study published in the Journal of the American Medical Association](#), are a quarter of elderly Medicare patients still dying in hospitals? Forty percent of these seniors are finding their deathbed only at the end of a harrowing, convoluted and expensive medical path that sees them being physically moved from one setting to another at least three times in the last few weeks before death.

The answer to the above question is as complex as the path, but there is a straightforward alternative that could improve the quality of end-of-life care while reducing the outsized costs our healthcare system cannot support.

The High Costs of the American Way of Dying

The 2010 Affordable Care Act was enacted (in part) to reduce the rising and unsustainable cost of healthcare while improving its quality. It's no secret that U.S. healthcare costs have been skyrocketing for decades. According to the Centers for Medicare & Medicaid Services, at its current pace, [total healthcare spending is expected to reach \\$4.8 trillion in 2021](#). That's up from \$2.6 trillion in 2010, which was up from \$75 billion in 1970. This means that at its present rate of growth, healthcare by 2021 will account for a fifth of the U.S. economy.

Contributing to these rising costs is the aging of America. In 2009, [there were 39.6 million Americans over age 65, representing nearly 13 percent of the population](#). By 2030, there will be about 72.1 million, accounting for almost a fifth of the population. A growing, aging population, afflicted with the chronic illnesses that consume greater healthcare resources, guarantees that costs will continue to rise unless something is done.

Right now, patients with chronic illnesses in their last two years of life [account for about a third of total](#)

[Medicare spending](#). While it makes sense that the sickest people would account for a large percentage of healthcare spending, many of those costs might be avoided through a more informed, evidence-based approach to end-of-life care. If, for example, people were more educated as to the likely outcomes of end-of-life interventions or if patients had the opportunity to see their expressed (if largely undocumented) wishes concerning the nature of their end-of-life care realized, those costs likely would decline.

The cost of end-of-life care is disproportionate even when one takes into account an older, sicker patient population. The Dartmouth Atlas study found that 17 percent of Medicare's \$550 billion annual budget is spent on patients' last six months of life. In 2012, [Medicare paid \\$55 billion just for doctor and hospital bills during the last two months of patients' lives](#). When it comes to cancer, a 2007 National Institutes of Health study found that 78 percent of that spending occurs in the final month alone, when treatments often can be termed futile.

What do we mean by futile? According to the Dartmouth Atlas study, "populations living in regions with lower intensity of care in the last six months of life

[did not have higher mortality rates than those living in regions with higher care intensity.](#)” In short, the end-of-life treatments that patients and their family members believe will extend life largely don’t. These treatments are futile. They may extend life briefly, but they do not achieve outcomes that patients can appreciate or would choose if the ramifications clearly were understood beforehand. More important, the emotional toll and sense of loss generated cannot be calculated.

Not only largely futile and painful, these end-of-life interventions are expensive. The average cost for a day of futile treatment in an intensive care unit is about \$4,000, according to a 2013 UCLA-RAND study. For 123 patients deemed to have received futile ICU care, total

uncoordinated care. This level of activity places a strain on patients, drives higher costs, and, in the whirl of doctors and treatments, makes it easier for professional caregivers to avoid difficult conversations about end-of-life care and outcomes while making it harder for patients and their family members to have such dialogs.

However, despite the broad circulation of these and other data encouraging a change in end-of-life treatment practices, Medicare spending on patients over the last two years of their life increased 13 percent from 2007 to 2010, indicating that the problem is getting worse, not better. Meanwhile, enormous amounts of money and emotion are being wasted on futile care.

debates often have “a greater chance of receiving the preferred treatment” and tend to take greater advantage of palliative and hospice care, avoiding the more aggressive interventions associated with “[poor quality of life and death, as well as higher costs and, in some cases, reduced survival.](#)”

For all these reasons and more, it’s time to stop deferring this conversation.

Why a Simple Conversation Can Be So Hard

Physicians are trained to combat death. Death is the enemy, and surrender — admitting that a patient cannot be cured, that death cannot be denied — is terribly difficult. Doctors want to preserve hope and, according to the American Psychological Association, in general, have difficulty acknowledging — both to themselves and to their patients — [that a cure may not be possible.](#) Doctors fear that suggesting palliative or hospice care may imply that they have given up or failed.

Eventually, this can lead to the delivery of futile care even as doctors and their patients, aware of new technologies and treatments, make every attempt to prolong life.

Physicians also have been found to [overestimate the efficacy of trying certain interventions.](#) In a recent study when the physicians of almost 500 terminally ill patients were asked to predict how long the patients would survive, 63 percent overestimated survival time. The average forecast was five times too high.

Many physicians are uncomfortable asking patients (or their family members) about choices (hospital or home treatment, breathing machines or feedings tubes, or comfort care), believing that to be a dereliction of responsibility to patients. Nor do most medical schools place a sufficiently high importance on training physicians to focus on managing symptoms or providing patients with emotional support.

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costs during the three months of the study came to \$2.6 million at five ICUs. That’s \$2.6 million spent for 123 people for 90 days that likely contained very few decent moments.

These futile interventions degrade the quality of the patients’ last days as they are subjected to the well-meaning but ultimately wearying and confusing ministrations of an ever-increasing cohort of medical caregivers. Aggressive end-of-life treatment has been found to be associated with “[worse patient quality of life and worse bereavement adjustment.](#)” According to a 2013 Dartmouth study, the percentage of cancer patients who saw 10 or more physicians during the last six months of life increased from 42 percent in 2003-2007 to 58 percent in 2010, suggesting that those last six months are marked by increasingly fragmented,

What has been shown to change this dysfunctional pattern, lower costs and improve quality are end-of-life advance planning sessions. These are early-in-the-process discussions among the patient, family and physicians. The patient is provided with comprehensible data about the outcomes of treatments, presented with a variety of options that include palliative care and in-home as well as in-hospital hospice, and then is encouraged to express and document one’s wishes, making informed decisions at a time when a patient is best capable of doing so.

Unfortunately, for the majority of people, these deliberations are not occurring. Physicians are not trained to conduct these types of meetings, and hospitals generally do not have processes to encourage or facilitate such talks. Patients who do enter into these

It is not surprising that a 2011 report for the UK's Commonwealth Fund found that in the United States, [“communication about end-of-life care between patients \(or their family members\) and the patient-care team is inadequate.”](#)

If the last months of life are difficult for medical professionals, these final days truly are heart wrenching for patients and their family members. In this highly charged emotional period, it nearly is impossible to make considered decisions or even to know what one wants. And though hospice care is being used today by a greater percentage of the patient population, 28 percent of patients who were in hospice care at the time of death in 2009 had been there for three days or less, indicating that hospice still is subordinate to aggressive end-of-life hospital-based interventions. Indeed, the most common feedback from hospice patients' family members is that they wish their relative had gone to hospice sooner and had spent more time there.

Both doctors and patients are uninformed about the type of care that can continue, often elegantly, when intervention stops, as the fields of palliative and hospice care, both hospital and home based, are as underappreciated in clinical settings as they are by consumers. Culturally, conversations about death, unless they center on how to stave it off, still are somewhat taboo in the United States (as evidenced by the discussion of so-called “death panels” during the nationwide debate over the Affordable Care Act).

Another reason why the manifest benefits of advance end-of-life planning are so rarely realized is built into the structure of the American healthcare system. It remains predominantly run on a fee-for-service basis, which means that providers are rewarded for doing more, not less, and quality of life does not always figure into that calculation. While the 2010 Affordable Care Act will drive providers to adopt (and payers to support) care models that increasingly will offer rewards for good patient outcomes and penalties – both financial

and competitive – for substandard quality or the inefficient use of resources, the fee-for-service model will not vanish overnight.

However, to prepare for success in this evolving healthcare landscape, it will behoove institutional providers to start programs now that will provide care that is both better and less expensive than it is today. In the reimbursement models emerging from the Affordable Care Act, providers will not want to perform, nor be able to afford, procedures and treatments that do not provide tangible patient benefits.

The Talking Cure: Advance End-of-Life Planning

Thanks to the proliferation and accessibility of information on the Internet, and the society-wide empowerment of customers in our increasingly digital society, patients are becoming ever-more savvy consumers

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of healthcare. Patients want to be more informed as to the costs and benefits of the treatments pursued and approved. To speak with patients in a more responsive and thoughtful fashion, institutional providers should be formulating advance end-of-life planning programs and discussions aimed at educating patients and improving their own and their family's end-of-life experience. These sessions also will help physicians deliver more appropriate, effective and compassionate care while lowering system-wide costs.

Advance end-of-life planning is composed of reflection, discussion

and communication of preferences for end-of-life care that precedes and guides end-of-life protocols, directives, choices and treatments. This planning is best done well before a crisis, when individuals likely are relatively young and healthy. The consequent plan must be dynamic, changing as the patient's health evolves during the course of illness.

These plans cannot be off the cuff; they must become a standard part of patient care, ideally primary care. And along with the quality-of-life benefits that such plans provide patients and providers, a 2009 study found that [costs were 35.7 percent lower](#) for patients who had formal end-of-life discussions involving medical caregivers and family compared with those who had not.

This opportunity to lower costs should drive medical professionals to conduct broadly inclusive advance end-of-life discussions that will enable medics

to make more realistic, effective and caring decisions about treatment protocols. It also will establish a new openness to alternative ways of caring for people at the end of their lives that are better aligned with patient wishes. Finally, these discourses help prevent the uncoordinated, fragmented care that can lead to poor clinical decision making and negative experiences for all involved.

The decisions that emerge from these conferences must be driven by the collection and analysis of data produced by medical centers and physicians. Taking a hard, analytic look at outcomes will educate professional

caregivers as to the predictability of death. Sudden death in hospitals now is more the exception than the norm. Understanding that, clinical leaders can prioritize efforts to create better end-of-life experiences for patients receiving the highest proportion of futile care. This also will help clinical leadership appreciate the financial implications of interventions that do not improve outcomes.

Fortunately, currently available technologies can be used to collect and analyze these data and, in some instances, provide ways to directly improve the quality of end-of-life care. For example, [a 2013 study of 100 people with advanced lung cancer](#) found that if their oncologists received automated e-mail alerts when patients' chemotherapy regimens changed, doctors were more likely to document their patients' end-of-life wishes before the patients' conditions worsened. More than a third of those patients whose doctors had received alerts had patient wishes documented in the electronic health records. Conversely, only 15 percent of patients whose oncologists did not get these alerts had end-of-life preferences documented.

In addition to making the best use of new technologies, clinical ethics experts can train physicians and design educational programs to

inculcate a more compassionate and responsible approach to end-of-life care, rethinking the ways hospital resources are deployed. These programs should provide both patients and providers with the tools to have fruitful, comprehensive discussions about how to address the final stages of terminal diseases, including palliative care programs, which should be instituted where they do not exist and enhanced where they do.

Indeed, some forward-looking institutions already are implementing these solutions and are achieving success.

The University of Pittsburgh Medical Center, for example, [reduced in-patient days in the last six months of life by 20 percent. It also reduced ICU days by 16 percent.](#) The hospital did so by implementing less aggressive end-of-life intervention protocols. These new protocols were [based on leveraging patient data upon admission to the ICU](#) and using the predictability of outcomes to guide treatment. And a recent study by the Canadian Hospice Palliative Care Association estimated that hospital-based palliative care could [reduce the cost of end-of-life care by 50 percent](#) (primarily by reducing ICU admissions).

Yet much of the burden for reducing costs incurred during end-of-life

treatment while improving quality still will fall upon individual physicians. They must be trained both to better assess patients and to communicate more effectively what medicine can and cannot do.

A Change Long Overdue

As clinical leaders in the era of the Affordable Care Act increasingly become economically accountable for the care they deliver and begin to focus more intently upon improving quality and outcomes while reducing costs, the end-of-life period offers the ability to do both. This, inevitably, will align with the wishes of patients who also will become increasingly responsible for their own care and will wish to be better informed as to all aspects of potential procedures and treatments, especially those that affect the quality of life in the final years, months and days.

With improved, patient-focused end-of-life care involving advance planning in an open, informed atmosphere, there is a great opportunity to create a more positive experience for patients and their family members, as well as hospital staff, while conserving dollars for patients who will most benefit from modern medicine's powerful, life-sustaining tools. ■

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