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Health Care Costs and Choices in the Last Years of Life

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Many U.S. patients endure pointless treatments because their doctors don't know how to talk about death. But that's changing as hospice and palliative care are gaining ground.

As a Scottish-Canadian-Californian, I have always said that I have a unique perspective on health care and all things to do with health care, including death and dying: The Scots see death as imminent. Canadians see death as inevitable. And Californians see death as optional.

I wrote that joke more than 20 years ago and continue to use it because it tells a fundamental truth: that Americans and the American health care system are uncomfortable with the inevitability of mortality.

Patients and families consistently report preferences to die peacefully at home, but all too often we die in hospitals with a highly medicalized and uncomfortable end. This column will explore the economic and societal issues of end-of-life care for an aging society. How does the United States rate versus other countries, and what are the opportunities for hospitals and health systems to improve care at the end of life?

Care and Costs in the Very Old

Let's start with a fact base. We are all going to die. And the chances are that more of us will die at an older age. By 2050, the number of people on Medicare who are 80 and older will nearly triple; the number of people in their 90s and 100s will quadruple.

Recent analysis of Medicare claims data (excluding Medicare Advantage enrollees) conducted by the Kaiser Family Foundation found that Medicare spending rises with age and peaks at 96, declining slightly at older ages. Spending at age 96 is $16,145, more than double the per capita spending at age 70 ($7,566). Even excluding those who died in the given year, the pattern persists. Interestingly, the peak age of spending varies with the Medicare service line; for example, inpatient per capita spending peaks at age 89, Part B and D drugs at 83 and outpatient at 83. Services such as hospice peak at 104 years of age, skilled nursing facilities at 98 and home health at 96.

We are living longer and consuming services at an increasingly intense rate well into our 90s. And this Kaiser Family Foundation analysis, by its own admission, underestimates the health care costs of the very old, because it does not include Medicaid, the principle payer for nursing home expenses.

Indeed, the Centers for Medicare & Medicaid Services develops estimates of age-specific cost estimates for all expenditures for all payers. The estimates show that between 2002 and 2010, per capita spending for those 65 to 84 years old grew 36 percent from $11,692 per capita to $15,857 per capita, while per capita spending for those older than 85 grew by 38 percent from $25,192 to $34,783 over the same period. This reflects a pattern of rising age-specific utilization rates that has been documented in many countries including the United States: Over time, we treat older generations more intensely.

International Comparisons

Most other developed countries are much older than we are. I don't mean castles and battles; I am talking percentage of the population older than 65. From the Scandinavian countries to Japan, many developed countries have more than 20 percent of their population in that age group compared with only 13 percent in the United States.

They are experiencing the same phenomena we are — upward-bending, age-specific utilization rates — which in layman's terms means they are doing more for the average 75-year-old patient than they did 10 years ago in Scandinavia, Germany, France and so forth. The rates are probably much steeper in the United States, but it is difficult to get reliable age-specific data for international comparison.

One recent window on international differences in care for the elderly is provided by the excellent work of the Commonwealth Fund, which conducted international surveys of the elderly in 11 countries and found that:

"U.S. older adults were sicker than their counterparts abroad. Out-of-pocket expenses posed greater problems in the United States than elsewhere. Accessing primary care and avoiding the emergency department tended to be more difficult in the United States, Canada, and Sweden than in other surveyed countries. One-fifth or more of older adults reported receiving uncoordinated care in all countries except France. U.S. respondents were among the most likely to have discussed health-promoting behaviors with a clinician, to have a chronic care plan tailored to their daily life, and to have engaged in end-of-life care planning. Finally, in half of the countries, one-fifth or more of chronically ill adults were caregivers themselves."

Interestingly, we may be behind other countries in primary care provision and out-of-pocket burdens, but we are seemingly ahead in prevention among the elderly, for chronic care planning and in end-of-life planning — all of which seem to be positive attributes.

Strikingly, the U.S. elderly seemed to be sicker, with 68 percent having two or more chronic conditions compared with the next highest, Canada, at 56 percent, and the lowest, the UK, with only 33 percent. It may be that we in the United States look for more things and get diagnosed and treated more aggressively. As my old friend Bill Rosenberg of PWC likes to say: "Good health is a state of incomplete diagnosis."

Health Care Costs in the Last Year of Life

What about the last year of life? Isn't that where all the money is? As policy guru Ezekiel (Zeke) Emanuel wrote in a *New York Times* editorial in 2013:

"Wrong. Here are the real numbers. The roughly 6 percent of Medicare patients who die each year do make up a large proportion of Medicare costs: 27 to 30 percent. But this figure has not changed significantly in decades. And the total number of Americans, not just older people, who die every year — less than 1 percent of the population — account for much less of total health care spending, just 10 to 12 percent."

So the last year of life is not the only source of high spending; rather, it is a pattern of intense medicalization of aging and disability for an aging society.

Confronting Mortality: Three Gurus

Mortality is getting attention. Atul Gawande, arguably the leading medical writer, thinker and communicator of our generation, has taken on end-of-life care from his perspective as son and surgeon.

Gawande's new book, *Being Mortal*, as well as his "Frontline" film and accompanying articles and interviews, beautifully document the pain and dilemmas of dealing with mortality from the perspectives of physicians, patients

and family members. On one hand, doctors want to provide hope to patients that they can be returned to their lives whole and healthy. On the other hand, physicians understand (when patients often do not) that the chances of treatment and interventions delivering on that promise are often pretty slim. And that, particularly for those of advanced years or with serious medical conditions such as advanced cancers, death is more likely than a return to a full life.

Even when doctors know the odds, they find it hard to talk about it. And, all too often, the medical system just takes over and we keep doing things to patients without their fully realizing that they are not going to get "better" in the true sense of the word.

Gawande's stories of his own and his colleagues' patients as well as the experience of his own father's illness and death poignantly portray the key dilemmas of being mortal.

Patients, families and providers are ill-equipped to have the candid, open dialogue about preferences, probabilities and planning for the end. Instead, all too often, physicians "do their best" or "do everything they can" but still come up short of preventing mortality, while in many cases aggravating morbidity and eroding the quality of life remaining.

Hope is a wonderful thing. False hope can be cruel.

Gawande's work reveals that end-of-life care is about listening to patients and engaging them in honest dialogue about options and outcomes — easy to say, but excruciatingly hard to do. I salute those who do this work every day with skill and compassion.

Gawande will be one of the keynoters at this year's Health Forum and the American Hospital Association Leadership Summit in San Francisco, and I look forward to hearing his views.

Another high-profile health care guru, the aforementioned Zeke Emanuel, drew a lot of attention for his recent *Atlantic* article explaining that he wanted to die by 75. I put it in my calendar to check in with him when he is 74.

But as an oncologist and bioethicist, as well as a leading health policy leader, Emanuel is remarkably well-qualified to make the case that longevity without vitality is overrated. His general point is that we can't really expect "the compression of morbidity" (a short period of unpleasantness at the end of a high-functioning life) which bursts the bubble on what he terms a "uniquely American idea."

I have many friends in their late 70s and 80s who, despite the aches and pains with which all of us are too familiar, are high performers, still enjoying golf, ice hockey (the Canadians, eh?), skiing, sailing and even running marathons. They are active and engaged.

Indeed, the Blue Zone movement identified enclaves around the world in which the combination of never retiring from work, walking, social engagement, a glass of wine and a nap every afternoon seemed to lead to longevity without impairment. That's my plan.

But Zeke is probably right: Most of us won't be that lucky.

My third guru on mortality is my old friend Richard Smith — doctor, writer and philosopher king who served as editor of the *British Medical Journal* for more than 20 years and then became a globe-trotting evangelist for the improvement of chronic care. Richard is a blast to follow on Twitter: erudite, enthusiastic and engaged in multiple issues of health and society on a global basis, and who's funny as hell.

For the last few years Richard has become very interested in death, but not in a morbid way, LOL. He emphasizes the role that death plays in life's journey and draws from the great poets and writers of how mortality and morbidity are all part of being human. Richard's central thesis is that overt and unwarranted medicalization of the human journey may be counterproductive and harmful. Enjoy life while you have it, but embrace the whole journey, including death.

Encouraging Trends

There are encouraging trends in care for the elderly at the end of life.

The rise of palliative care and hospice. Despite the temporary derailment of death panels, the hospice and palliative care movement keeps gaining momentum. There were more than 5,800 hospice organizations in 2013, up from 5,000 in 2009, according to industry statistics. These organizations served 1.54 million patients in 2013, up from 1.34 million in 2009. The National Hospital and Palliative Care Organization (NHPCO) estimates that, in 2013, a full 1.11 million deaths occurred while under the care of hospice. (Total deaths in 2013 were 2.6 million, implying that 42 percent of deaths occurred in hospice.)

A rigorous analysis of Medicare claims data for decedents by Joan Teno, M.D., found that "of all Medicare decedents in the year 2001, 18.8 percent accessed hospice for three or more days. By 2007, the proportion of Medicare decedents accessing three or more days of hospice services had increased to 30.1 percent."

The role of health systems. More and more health systems are embracing palliative care and hospice initiatives and embedding them in the chronic care continuum. Large systems from coast to coast, such as North Shore LIJ Health System in New York and Sharp HealthCare in San Diego, have developed integrated palliative and hospice care services as part of an integrated continuum of care — and as they pursue their journey from volume to value.

Integrating with plans and providers. Hospice and palliative care organizations historically have been relatively small-scale, independent entities, often volunteer and faith-based. Indeed, NHPCO data show that 78.7 percent of organizations have 500 or fewer admissions per year. As health plans and providers focus on the continuum of care, expect greater interest in partnership and, in select cases, consolidation of hospice organizations into larger entities. Similarly, managed care organizations operating in the dual-eligible Medicare advantage and Medicaid programs will be seeking partners with hospice and palliative care as managed care for the elderly population continues to grow. For example, California Sen. Ed Hernandez championed legislation SB 1004 requiring managed care plans that serve Medi-Cal patients to integrate palliative care into their service offerings. However, the Medicare hospice benefit remains the primary source of funding for hospice and palliative care organizations nationally, providing 87 percent of revenue in 2013.

Beyond just cancer care. While the hospice movement was borne out of the goal of serving terminal cancer patients, by 2013, those with cancer diagnoses accounted for 36 percent; dementia, at 15 percent of patients, was the second largest and most rapidly growing. Alzheimer's and dementia are massive national policy issues worthy of a whole column given to the developments in science and technology and the resulting costs that will ensue.

A Personal Note

My mother died of pancreatic cancer at age 82, seven years ago in Vancouver, British Columbia. When she took ill, she received very high-tech care (an endoscopic biliary stent) to prevent a rapid demise from jaundice; but her physicians made it crystal clear from the outset to my mother and to the family that she had terminal cancer and there was no therapy, treatment or surgery that would extend her life beyond a few months. She appreciated the honesty and enjoyed her four months, getting all her affairs in order and saying her goodbyes, while enduring any discomfort with dignity and class.

She had four great months at home and a good death supported by my brave and dedicated sister and a remarkable palliative care team of physicians and nurses who helped to keep her at home pain-free and in control of her own

life. She died on a snowy December night in my sister's arms with the Christmas lights twinkling and Johnny Mathis singing "Chances Are." It's what she wanted. We all deserve that chance.

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