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End-of-Life Care, Not End-of-Life Spending

Ashish K. Jha, MD, MPH

People in the United States spend a lot of money at the end of life. In fact, about one quarter of all Medicare spending goes toward care for people during their last year of life. Beyond this shockingly high number, we know that end-of-life care patterns and spending vary widely across hospitals and communities. For example, although about 1 in 8 elderly persons living in Utah die in the hospital, the number is nearly 3 times higher for those who live in New York.

The combination of high spending and variability in spending has convinced many policy makers that end-of-life care is an attractive target for health care savings, although many clinicians are skeptical.

Emerging evidence suggests that saving money on end-of-life care is much easier said than done. Instead of focusing on spending, we should focus on improving the well-being of those who are terminally ill.

High Costs of Sickness and Saving Lives

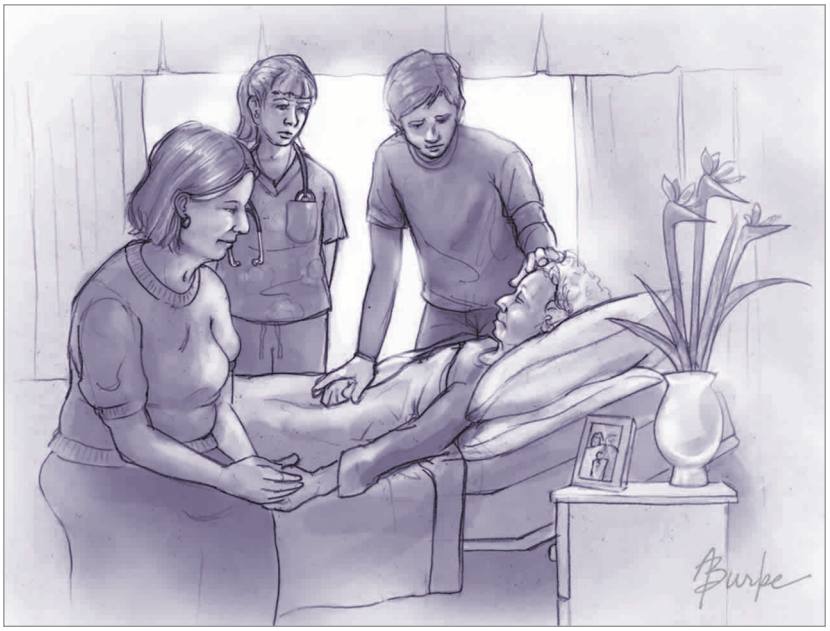
The major factor that makes end-of-life spending complicated is that our health care system spends a lot on people who are sick. Patients with multiple chronic diseases can spend upwards of $57 000 per year on their health care. A person with cancer who is undergoing treatment may spend up to $25 000 in just the first month after their diagnosis. Of course, some of these very sick people will die, but many will not, largely due to the care they receive.

Spending money on people who are sick is a good thing—caring for sick individuals is a primary mission of the health care system. And there is good evidence that more-intensive care for sick people can save lives. For example, patients who receive more intensive care in the hospital for conditions like acute myocardial infarction or congestive heart failure have a higher likelihood of survival compared with similar patients who receive less intensive care. End-of-life spending often gets confused with spending money on people who are sick because some of them ultimately die.

Imagine a scenario with 200 sick people in Miami whose average health care expenditures are about $10 000 per person per year, and 100 of them die within the year. The average end-of-life spending per person for this population will be $10 000. Now imagine another 200 sick people in Minneapolis, whose average health care expenditures are $5000 per person, but 150 of those people die. In Minneapolis, the average end-of-life spending will be seen as much lower—only $5000 per person—but of course, this fails to take into account how many additional people in Miami survived. Cutting spending in Miami to match that of Minneapolis may not be a particularly good idea.

One way to potentially save money is to reliably predict who will die and therefore would not benefit from receiving intensive care. But this turns out to be extremely hard to do. In a recent article in *Science*, researchers used a sophisticated machine-learning prediction tool to identify patients who are most likely to die, and found that there is no group of people for whom death is easily predictable. In addition, patients with high predicted mortality do not necessarily incur larger expenses. If it's not possible to reliably predict which sick people are going to die, then reducing end-of-life spending becomes extremely difficult.

Anecdotally, it seems one can identify instances in which it's possible to make these sorts of predictions: for patients with advanced metastatic pancreatic cancer, for example, where we know that life expectancy will be short. But it turns out that knowing exactly when someone with a terminal illness is going to die is difficult—and for many of these patients, additional weeks or months with their families can be extremely meaningful. Furthermore, a much more common scenario involves people with an advanced chronic illness, such as a patient with congestive heart failure. Such patients may spend years cycling in and out of the hospital and then have a sudden exacerbation that leads to their death. Knowing when to cut back, when to stop intervening and providing intensive care is clinically and socially difficult.



Shifting Focus

Given the difficulties in saving money on end-of-life care, should efforts to change the care for these patients be abandoned? Not at all. The problem isn't that such care is unworthy of focus; instead, we may be focusing on the wrong problem. The problem is less about wasteful spending and more about poor quality of care. We need to focus on providing high-quality, patient-centered care at the end of life.

Patients with advanced illness frequently receive care that is discordant from their personal preferences. Most people indicate that they would prefer to die at home, yet more than a fifth of patients still die in the hospital. In a study of family members of patients who died from cancer, only half of respondents reported that their loved one received excellent end-of-life care. This is the often-ignored area of end-of-life care on which we must focus our efforts.

It has been tempting to blame failures in end-of-life care on our fee-for-service payment systems with the hopes that alternative payment models like accountable care organizations will help. This seems unlikely. End-of-life spending is neither a new problem nor a uniquely US one. One study comparing end-of-life care for cancer patients older than 65 years in United States and 6 other countries found that the United States is by no means an outlier in terms of end-of-life care. In all of the countries in this analysis, patients frequently used acute care settings and chemotherapy within the last 180 days of life, and many died in acute care settings. Additionally, although the United States does spend vast amounts of money on end-of-life care, both Canada and Norway spent more per capita than the United States in the last 180 days of life. Clearly no country, regardless of the type of payment model they use, has figured out exactly how to care for patients at the end of life or how to predict who needs that care and who doesn't.

Ultimately, our failings in adequately caring for patients at the end of life come from the difficulties we have, both as patients and physicians, in confronting mortality. This is not a health care financing problem, but a fundamentally human problem. Physicians and nurses are often hesitant to have discussions with patients about their care preferences near the end of life. Care at the end of life is every bit as important as policy makers have thought, just not for the reasons often cited. We need to refocus our efforts toward end-of-life care so that we can better identify the needs of patients with advanced illness, and then offer intensive treatment when patients want it, help enable a more peaceful death when they don't, and learn how to manage that transition. It's essential to avoid getting distracted by promises of cost savings along the way. ■

Author Affiliation: K. T. Li Professor of Global Health and Health Policy at the Harvard T. H. Chan School of Public Health.

Corresponding Author: Ashish K. Jha, MD, MPH (ajha@hsph.harvard.edu).

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