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Medicare spends a considerable amount of money on beneficiaries in their last year of life. This is often thought to be an issue of cost versus the intensity of care that end-of-life patients should receive. This way of framing the debate, however, overstates the importance of end-of-life spending, which is quantitatively modest compared to an ever-increasing Medicare budget. More salient is whether patients are receiving end-of-life care that matches their values and beliefs. Unfortunately, the evidence suggests that Medicare’s tendency toward providing end-of-life care in a hospital inpatient setting is at odds with the preferences of patients.

On January 1, 2011, the Obama administration took a courageous but short-lived stand to address one of the most significant problems in US health care. It began reimbursing physicians for voluntary consultations with Medicare patients about end-of-life care—euphemistically known as “advance care planning”—to educate patients about possible future health care decisions before they are in a medical crisis. Unfortunately, the administration suspended this policy a week later in the face of withering criticism. The proposed Medicare rule—welcome to many physicians—failed to survive accusations that it

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Key points in this Outlook:

- Reducing end-of-life costs will do little to curb the growth in Medicare spending overall. But end-of-life care provision should be reformed to match the values of patients, many of whom lack the tools to make informed decisions about end-of-life care.
- Medicare's incentive structure rewards providers who “do more” but not providers who spend more time counseling patients or eliciting their end-of-life treatment preferences.
- Medicare should compensate physicians for providing end-of-life care counseling. Such a physician-centered approach stands in contrast to payer-centric approaches that attempt to allocate care according to rigid cost-effectiveness criteria.

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would limit choices and access to care sought by severely ill people. On the contrary, it represents a small but needed step toward reforms that would provide patients with greater, more informed, and more individualized choices for end-of-life care.

The Medicare program faces a bleak fiscal future. Major reforms that change the way Medicare delivers end-of-life care are inevitable. With one-quarter of program outlays spent on the last year of life, end-of-life care seems like low-hanging fruit to many policymakers and analysts. These end-of-life experiences vary widely across parts of the country, with as many as 45 percent of Medicare beneficiaries dying in acute care hospitals. Only 55 percent of cancer patients use hospice care—designed to deliver supportive care in a humane and compassionate manner—during the final month of life.

Pressure for reform will only continue to grow with the burgeoning elderly population. The kind of care and the quality of life that this population will value and prefer when facing life-limiting illness will vary widely. Regardless of when and how end-of-life reforms take shape, new Medicare policy and practices must account for the varied and nuanced situations that individual seniors will face. Patients must be able to make informed decisions consistent with their own values, balancing the use of aggressive treatments with small-to-moderate chances of success against quality-of-life considerations and financial cost.

**Medicare Spending at the End of Life**

It is no secret that Medicare spends a great deal at the end of life, but despite the attention paid to this issue, few meaningful reforms have been enacted, and little has changed. The actual trend in spending as a percentage of Medicare's budget has remained fairly constant for decades, with only the slightest signs of abatement.

![Figure 1](image-url)

**Figure 1**

Percentage of Medicare Spending by Beneficiaries Who Died in a Given Year

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*Figure 1 illustrates the share of inpatient, overall, and drug spending by Medicare beneficiaries who died in a given year, reported annually from 1992 to 2006. The "inpatient only" series implies that about one-fifth of Medicare's inpatient hospital spending is generated by the roughly 5 percent of Medicare beneficiaries who die in a given year. These beneficiaries also generate over 10 percent of all spending, but a disproportionately low share of drug spending. If we were to expand this calculation to all spending by patients with less than twelve months to live—and thus include some individuals who will die early in the subsequent year—we would see a similarly stable, but higher, series accounting for about one-quarter of Medicare spending annually.*

Both the persistence of these patterns and these magnitudes demonstrate that end-of-life spending is not necessarily about cost containment. For example, when we take the expansive group of all patients with less than twelve months to live and reduce their spending to that of a typical Medicare beneficiary, we find that this would save Medicare 20 percent of its spending on a one-time basis. While this sounds like a large number, it is fairly modest in the scheme of Medicare cost growth. Given
recent annual increases in Medicare spending of nearly 8 percent, even this drastic and wildly unrealistic reversal would deliver little more than a two-year moratorium on cost growth.\(^5\) Significantly, end-of-life spending is substantial, but it has not been growing faster than the overall program, as evidenced by its stable share of total spending.

As a result, focusing on reducing end-of-life costs will do little to curb growth in Medicare spending overall. It is a one-time windfall to the program that does not substantially alter Medicare’s fiscal future. Therefore, because containing end-of-life costs are unlikely to curb the troubling growth in Medicare spending, they should not be overemphasized when looking for ways to control costs in the broader Medicare program.

Rather, the most salient question should be whether end-of-life Medicare beneficiaries are getting the kind of care that provides them with a higher quality of life and is consistent with their values.

At present, this care is strongly skewed toward the hospital inpatient setting. According to table 1, more than 82 percent of spending on beneficiaries in their last three months of life goes to Medicare Part A, which is the component of the Medicare program that finances inpatient hospital care. This contrasts with other beneficiaries, whose quarterly spending is split almost evenly between Part A inpatient costs and Part B, which covers physician visits, outpatient surgeries, tests, and other ambulatory procedures.

There is a steady trend toward greater inpatient (Medicare Part A) spending as the end of life nears. Figure 2 breaks down these spending patterns by months of life remaining. Eighty-five percent of spending goes to inpatient care in the last month of life, compared to 77 percent for patients with six months to live.
Diversity of Preferences for End-of-Life Care

Medicare spending near the end of life tilts toward inpatient care and away from all other forms of care, including physicians, hospice care, palliative drugs, therapeutic drugs, and other therapies. However, many patients say they are not in favor of heroic measures at the end of life. Surveys of Medicare beneficiaries indicate that most want to spend their last days at home without using mechanical ventilation and life-prolonging therapies that decrease their quality of life.6 These findings suggest a clear disconnect between the desires of patients for a more peaceful death and the outcomes of a system in which some areas place almost half of Medicare beneficiaries in acute-care hospitals during their last days of life.

Yet reforming end-of-life care is not simply, or even substantially, about limiting hospital care for patients near the end of life. There is considerable diversity among patients in preferences for end-of-life care. For example, while a number of patients express a desire to limit aggressive care, many are also willing to spend their own money, not that of their insurance company, on expensive treatments with modest life-expectancy effects. This is particularly true when clinical circumstances make it hard to know when one is at the end of life. A cancer patient may face extremely long odds of surviving for one more year—maybe 5 percent—yet that patient cannot know whether she belongs to the 95 percent majority or the 5 percent minority.

Perhaps for this reason, many severely ill patients place substantial value on treatments with even modest chances of extending their life. Cancer patients often experience what can be called the “Lance Armstrong effect”—a hope that a new treatment for a fatal disease will reverse the disease course and allow them to return to life before the disease. These beliefs are reflected in patient behavior. Even those with bare-bones insurance are willing to spend substantial amounts out of pocket for cancer treatments with little chance of success. We have estimated the value to patients of expensive specialty oncology products (some of which deliver only days of additional life) at $500,000 per life year gained, based on willingness to spend out of their own pockets on high-cost chemotherapy regimens.7

The value placed on “speculative” treatments adds nuance to the picture of patient preferences. On the one hand, when patients believe they are at the very end of life, they dislike heroic measures. On the other hand, if there is still a small chance for recovery, many patients are willing to gamble significant amounts of their savings on it. Fundamentally, patients never know for sure when their lives will end, and the degree of this uncertainty matters. Patients will gamble on fairly modest chances for survival, but as these chances shrink from modest to negligible, they turn away from aggressive care.

One reason for the high value of life extension observed in many severely ill patients is simply that life is more valuable to someone who has less of it left. Ordinary people recognize this point, but our most commonly used metrics for valuing end-of-life care do not. Surveys demonstrate that people are reluctant to forgo care for the elderly, even if the resources could be more effectively used elsewhere. People also favor interventions that make the lives of the sick few much better off over interventions that make the lives of many only slightly better off. Even in the United Kingdom, where end-of-life care is heavily regulated by the National Health Service, growing complaints about denials of costly treatments for life-threatening diseases have prompted a compassionate-care exception to the rules and a reexamination of end-of-life care reimbursement.9 Some have criticized a national health system that makes coverage decisions based on its own resource constraints, rather than the preferences and values of patients and society.10

Patient-Centered Decision Making at the End of Life

The evidence suggests that outcomes in the United States do not match the distaste for aggressive inpatient care at the end of life. Outcomes overseas, however, do not match the desire for treatments that provide modest chances of life extension for people facing large risks of death. We need a third way forward that aligns the preferences of patients with the types of medical care provided. The policy debate over end-of-life care planning has equated it with “rationing” that would limit access to care. This is a simplistic and misleading view of the facts. This is easiest to see when we compare it to an

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environment in which a public health insurer explicitly rations care, as in the United Kingdom. The approach there has revolved around the use of cost-effectiveness criteria to determine how to allocate resources at the end of life. For example, a treatment that extends life by an average of one year and costs $80,000 might be denied in favor of one that adds an average of six months and costs $25,000. The cost-effectiveness approach argues for the adoption of technologies that cost less per life year gained and the exclusion of technologies that cost more. Conceptually, the idea is that a given extension of life has a certain (finite) value, and society should not pay costs in excess of this value. The trouble, of course, is the impossibility of finding a single, universally applicable “value” for a gain in life expectancy or health. In practice, cost-effectiveness regimes deal with this problem by carving out “compassionate care,” “unmet need,” and other exceptions to the basic principle. The result is a centralized system that lacks both transparency and accountability to patients and their physicians.

The solution is not to rely on governments or private payers to make binary treatment decisions based on narrow policy that considers all patients to be the same. Rather, public and private payers should encourage physicians to embrace their role as counselors who can educate patients about the realistic benefits—and harms—of each approach. Physicians are uniquely positioned to help patients determine the strategy that works best with their own clinical circumstances and values. This collaboration of physician and patient is a process, rather than a one-time discussion, and it ought to begin well before patients face hard decisions near the end of life. Under the current Medicare system, physicians are not compensated, and are often penalized, for investing time and effort into this lengthy but important process.

Medicare pays physicians a limited and fixed sum for the counsel received in a short office visit and additional amounts for tests, procedures, and surgeries that the physician performs. In effect, physicians are paid to do things to patients, not to listen, talk to them, or counsel them. Culturally, too, physicians may be more comfortable with administering treatments in the hope of achieving some clinical benefit, instead of spending their time discussing death or ending care. Ultimately, if Americans want a system that is centered on the autonomy of patients making decisions that are informed by the guidance of their physicians, the United States must begin to train and compensate physicians for participating in this decision-making process.

Rather than universally excluding some technologies and including others, the model of autonomous physicians relies on the principle that patients, educated by properly incentivized physicians, can be trusted to seek care that provides the greatest benefit and accords with their values and to refuse care that does not. Naturally, patients differ in clinical circumstance and values; society is better off when we take this heterogeneity into account, and that is the appropriate role of individual physicians.

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In the end-of-life context, the autonomous physician model provides physicians with incentives to manage the treatment of patients, rather than simply administering those treatments. The reimbursement of advance care planning would remove the disincentives that financially penalize physicians for counseling patients. Effectively, it would attempt to level the playing field between providing information and advice, and conducting procedures, tests, and surgeries. This is a step toward addressing a larger and more systemic problem that cuts across all segments of the Medicare program. The one difference may be the availability of a simple and direct approach to the incentive problem in the end-of-life context by reimbursing physicians who provide counseling to their patients with life-threatening illnesses.

Informing Patient Decision Making

Patients and families appear to lack education and information about what end-of-life care will involve. This deficiency seems to contribute to suboptimal decision making by patients facing terminal illness. Studies of patients with end-stage kidney disease find that less than 10 percent of patients have a discussion with their nephrologists about symptoms to expect at the end of life or about available palliative care options. Roughly 60 percent regret their decision to start dialysis as a treatment for progressive kidney failure.

Efforts to educate patients about end-of-life issues—including symptoms to expect and palliative care
options—are important to ensure that patients have the right information for making decisions at the end of life. Two recent studies yield valuable insights into how important this type of “informed consent” may be. In one randomized controlled trial of patients with terminal lung cancer, half were randomized to early palliative care—treatment by physicians and social workers who are trained in the management of symptoms at the end of life, and half were not. Both groups ultimately chose to undergo chemotherapy equally often, but the group randomized to early palliative care chose to be hospitalized less in the last month of life, experiencing better quality of life, lower costs, and, strikingly, longer survival. This study underscores the nuanced nature of patient preferences: distaste for heroic inpatient care at the very end of life is not inconsistent with a desire for aggressive chemotherapy with even a modest chance of success.

A second, smaller randomized controlled trial of patients with malignant glioma (an aggressive brain cancer) compared a control group that underwent verbal discussions about end-of-life issues with a study group that underwent both verbal discussions and a video specifically designed to educate patients about end-of-life issues. Patients were asked to choose among several options: life-prolonging care, including further chemotherapy and aggressive inpatient care; basic care, which is less-aggressive conventional treatment of other comorbidities such as heart disease and bacterial infections; and comfort care, which involves only pain management and providing narcotics and antianxiety medications to offer comfort. Among patients receiving verbal discussions alone, 26 percent ultimately preferred life-prolonging care, 52 percent basic care, and 22 percent comfort care. Among patients randomized to the video as well, none preferred life-prolonging care, 4 percent preferred basic care, and 91 percent preferred comfort care; 4 percent were uncertain. This study makes clear that information changes behavior and thus suggests that patients are not making fully informed decisions about end-of-life care.

**End-of-Life Care Costs and Patient Welfare**

Reining in Medicare spending at the end of life will contribute only modestly to cost containment in Medicare, according to figure 1. Therefore, advance care counseling is ultimately more about aligning the health care system with the values of patients and less about cost containment. It is a strategy to provide patients with the care they value and to eliminate what they do not. The focus is on the well-being of patients and how to create incentives that encourage providers to pursue it.

The financing and incentive structure of Medicare plays the dominant role in end-of-life care for the elderly because the program bears the lion’s share of the publicly financed cost. Medicaid also plays a role through its financing of long-term skilled nursing facility care, but it comes in a fairly distant second. About one-fifth of the Medicare population is “dually eligible” for Medicaid by virtue of low-income or other medically needy status. Among the dually eligible population, approximately one-third die in acute-care hospitals, one-third in long-term care facilities, and the remainder in other settings. Since Medicare limits coverage of skilled nursing facilities to a maximum of thirty consecutive days, the burden of long-term care falls heavily on Medicaid. Even so, Medicare costs during the last year of life are about 50 percent higher than Medicaid costs among the dually eligible population. Considering that only one-fifth of Medicare beneficiaries are eligible for Medicaid, it becomes clear that Medicare is the biggest player by a large margin. As a result, Medicare’s incentive and financing structure plays the major role in allocating end-of-life care.

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**Conclusions**

Today’s Medicare system reimburses inpatient care, drugs, and procedures with few or no constraints. The evidence suggests that end-of-life patients place value on some, but not all, of these kinds of care. However, Medicare provides little incentive for physicians to counsel patients or elicit their preferences for particular kinds of care. Rather, the incentive is to provide more treatment of all kinds. Reimbursing advance care counseling takes a step toward correcting this deep misalignment of incentives. Better-informed patients are more likely to shift care toward areas they value and away from those they do not.

As currently configured, Medicare encourages physicians to perform more treatments at the end of life and fails to compensate physicians who take the time to...
understand their patients’ values and design an appropriate treatment plan. Equally as important as understanding patient preferences is realizing that many patients are neither prepared to make difficult choices nor educated on what they may mean for remaining quality of life.

Efforts to encourage advance care planning have triggered fears of the government taking control away from physicians and making universal decisions about which patients should and should not receive care. This reaction misses the mark. The alternative to centralized decision making begins with a cadre of physicians trained and encouraged to counsel patients about the realistic benefits—and harms—of different treatment approaches, in the context of the patient’s own preferences and values. The Obama administration took a modest step in this direction, and then pulled back. Some very sick patients and their families are the worse for it.

Notes

2. Dartmouth Atlas Group, Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness (Hanover, NH: Dartmouth Institute for Health Policy and Clinical Practice, 2011).
3. Medicare covers hospice care when a physician certifies that a patient is expected to die within six months.
4. Christopher Hogan et al., “Medicare Beneficiaries’ Costs of Care in the Last Year of Life.”