

Avoiding a “Death Panel” Redux

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ABSTRACT

This paper examines why the “Advance Care Planning Consultation” provision was removed from H.B. 3200, the House healthcare reform legislation, in 2009—despite the fact that an overwhelming majority of the American public is in favor of end-of-life consultations and advance care planning—and how something like it might have been able to be retained. Although the negative rhetoric surrounding the proposed legislation contributed to its failure, we contend that its demise was also caused by its failure to reflect the fundamental goal of end-of-life consultations—namely, facilitating open and honest conversations about end-of-life issues with patients and their families so that patients may begin to acknowledge the inevitable, make appropriate decisions for their end-of-life care, and, when the time comes, die in as much comfort and with as much dignity as possible. Any future legislation created to incentivize physician-initiated end-of-life planning needs to more explicitly reflect this goal in order to garner wider public and political support.

KEYWORDS: Healthcare reform, §1233, death panel, end-of-life consultations, advance care planning

Introduction

On August 11, 2009, a physician walked into my (N.P.'s) mother's hospital room, and when he introduced himself as a palliative care specialist, I was terrified. A little more than two years before, my mother, at the age of fifty, had been diagnosed with advanced ovarian cancer. After countless rounds of aggressive chemotherapy treatments, she had enjoyed a few short months of remission before an MRI revealed the cancer had returned and metastasized to her brain. Although we were told this meant the cancer was no longer "curable," none of the physicians said anything about my mother eventually dying or even used the word "death" in any context. And I never wanted them to. As ridiculous as it sounds, I had made it my ultimate goal to protect my mom from the fact that she was dying. In an attempt to prevent the physicians from giving us any kind of prognosis, I made sure to attend all doctor visits with my mom; I knew if I were in the exam room, she would not ask how long she had to live because, ironically, she was protecting me from the same reality. Neither of us wanted to hear the gravity of our situation, and, consequently, we never did. When it came to prognoses, the doctors were always silent.

Despite the fact that my mother and I avoided the topic, I did not believe we were in denial about her death. I truly believed that if her death was imminent, I would have heard *something* about it from her doctors. So, one could imagine my surprise—and terror—upon meeting the palliative care physician that day. I cordially shook his hand, though my true desire was to push him out the door and into the hallway so I could explain to him that he was not allowed to tell my mom the truth. Instead, I stood there quietly as he explained that he wanted to talk to my mother about her "options." He said he had seen her scans, and "things didn't look good." I couldn't understand why he offered this information unprovoked, since my mother had already asked her other physicians what the scans showed, and none would answer the question directly. In fact, my mom's oncologist came in just the day before to tell us about a new

chemo—this would be her fifth—that he wanted her to try. So, when the palliative care physician suggested that my mother stop treatment, focus on “being comfortable,” and consider hospice care, I couldn’t believe what I was hearing. I watched helplessly as my mom nodded her head in silence. I knew this was the moment I had been dreading for nearly two and a half years.

I don’t know what I expected to happen once my mother and I were finally told directly that she was going to die, but I certainly did not expect what I witnessed. When the doctor left the room and my mom made the decision to start hospice care, she cried for all of a minute before telling me how incredibly relieved she was and how good it felt to not have to “fight” anymore. It was difficult for me to comprehend my mother’s feelings. How was it that she could feel relieved? I could not believe that the conversation I had dreaded most, the words that I thought would destroy my mother, had made her feel such a deep and profound sense of peace.

At the time, I was engaged to be married, and I couldn’t bear the thought of my mother, the woman whom I had depended on and admired all my life, not being at the wedding. That day, we decided to move up the date of the ceremony. A few hours later, I listened as my mom explained to her friends and family who came to visit that she was going to start hospice care. I heard her say how happy she was with her decision and that she was excited for the upcoming wedding. It’s difficult to describe my mother’s demeanor that night; it was as if she was joyful. It is strange to think that someone could feel joy in the face of death, but that was my mother.

I never imagined, however, that her joy would be so short-lived. My mother died the very next day. At two o’clock in the morning, her last conscious moments were spent watching my fiancé and me exchange vows at her bedside in a dark hospital room.

Almost exactly one month prior to N.P.’s mother’s death, a new subsection entitled “Advance Care Planning Consultation” (ACPC) was added to §1233 of House Bill 3200 (America’s Affordable Health Care Choices Act of 2009) that would have reimbursed healthcare providers for engaging in voluntary discussions concerning end-of-life issues with Medicare

patients.¹ The ACPC, as originally proposed, would have required practitioners seeking reimbursement for the service to discuss a series of topics, including:

- [A]n explanation by the practitioner of advance care planning, including key questions and considerations, important steps, and suggested people to talk to[;]
- An explanation by the practitioner of advance directives, including living wills and durable powers of attorney, and their uses[;]
- An explanation by the practitioner of the role and responsibilities of a health care proxy[;]
- The provision by the practitioner of a list of national and State-specific resources to assist consumers and their families with advance care planning, including the national toll-free hotline, the advance care planning clearinghouses, and State legal service organizations ...[;]
- An explanation by the practitioner of the continuum of end-of-life services and supports available, including palliative care and hospice, and benefits for such services and supports that are available under this title[; and]
- [A]n explanation of orders regarding life sustaining treatment or similar orders....²

Although it did not incentivize physicians to have end-of-life conversations with terminally ill patients, like N.P.'s mother, who did not yet qualify for Medicare, the ACPC pointed to the unfortunate reality that many patient-physician conversations concerning end-of-life care happen too late, if they even happen at all.

Although the ACPC was helpful in that it brought the often-taboo topic of end-of-life care into the public discourse, it was soon rhetorically reduced to notions of “death panels” and government-imposed “euthanasia.”³ Commentators such as Sarah Palin and Betsy McCaughey were among the most egregious offenders.⁴ Legislators such as Representative Foxx of North Carolina echoed their comments by implying in remarks on the floor of the House that the health reform bill would “put seniors in a position of being put to death by their government.”⁵ Yet even more careful statements from legislators such as Senator Charles Grassley, raised a concern that “the purpose for [the ACPC] is to save money rather than to ensure appropriate care at the end of life.”⁶ In response to the firestorm over the ACPC, the Senate quickly dropped its provision.⁷ Although the House retained its own, modified, provision in the health reform bill it

ultimately passed (H.R. 3962),⁸ the Senate refused to consider it,⁹ and the ACPC never became law.

The sudden and fiery rhetorical attack upon this proposed legislation and its removal from the bill may be surprising to some, given that research suggests the American public is not opposed to, and may actually be in favor of, engaging in conversations about end-of-life care.¹⁰ In fact, a 2011 telephone survey conducted by the Regence Foundation and National Journal indicated that ninety-seven percent of those surveyed agreed that patients and families should be educated about palliative care and end-of-life options along with curative treatment, and eighty-six percent agreed that discussions about these end-of-life options should be covered by health insurance.¹¹ What is more, studies have shown that eighty-nine percent of the general public desire advance care planning—a process in which a patient establishes preferences concerning future healthcare decisions should he or she become incapacitated, which may lead him or her to create a living will or appoint a healthcare proxy.¹² Despite this apparent desire to take part in advance care planning, however, only twenty to thirty percent of American adults actually have written directives.¹³

The disparity between the number of those who desire to engage in end-of-life planning and the number who actually have advance directives is quite concerning. It may suggest that even patients who say they are open to topics like death and dying often avoid the subject when it comes to actual crises.¹⁴ However, it may also indicate that physicians are not engaging in or initiating end-of-life conversations, even when their patients would like them to do so.¹⁵

Although the Liaison Committee on Medical Education requires medical schools to incorporate training in end-of-life care in their curricula,¹⁶ a 2007 literature review found a substantial lack of standardization in curricula, ranging from informal instruction with minimal evaluation to a formal curriculum mandating twelve contact hours and objective evaluation.¹⁷ It further appears that many practicing physicians may avoid hard discussions about the patient's end-of-life care

or postpone them until quite late in the patient's disease course.¹⁸ These findings are troubling, considering that the failure of many physicians to clearly and frankly discuss end-of-life care with their patients and the frequent absence of advance directives for patients who have become incapacitated may lead to unwanted aggressive or invasive treatment, which in turn can significantly diminish the quality of life for the dying patient and negatively affect the grieving processes of the bereaved.¹⁹

If engaging in end-of-life conversations and advance care planning is not only desired by many Americans but may also significantly improve patient care at the end of life, why was a provision that provided reimbursement for physicians to engage in end-of-life planning through Medicare removed from legislation? If, as some researchers have suggested, reimbursements under Medicare “would have been a start” for encouraging these conversations, why was §1233 so vehemently opposed by politicians and citizens alike?²⁰ Both scholars and journalists have suggested that the heated and misleading rhetoric espoused by some of the ACPC's opposition, including references to “death panels” and the Nazi Aktion T4 program, led to both the intractable polarization surrounding this portion of the health reform bill and its inevitable failure.²¹ Accurate as this claim may be, it may only provide part of the picture. Clearly, the highly polarized and, on some ends, reckless public discourse surrounding the ACPC was a major player in its failure, but the proposed legislation's emphasis on mandatory “checklists” and regulation may have served as fodder for these fiery critiques. However, future legislation that squarely focuses on the broader and more fundamental goals of end-of-life consultations and deemphasizes administrative and documentary concerns, may have a greater chance for success in years to come, as health reform is implemented and memories of the battle over § 1233 fade.

The Power of Myth

While serving on a national panel gathered to discuss the end-of-life provision outlined in America's Affordable Health Care Choices Act, the CEO of the American Society of Clinical Oncology, Dr. Allen S. Lichter, said of the provision: "The quality of the patient's life goes up. The quality of the family's life goes up. More patients die at home, which is where eighty percent of Americans say they want to die. Now, when you do the cost analysis, it happens to save money. That's the sprinkles on the icing on top of the cake—that's not the cake."²² Nothing in the text of §1233 suggested that cost containment was a motive; the section mentioned nothing about costs, and was scrupulously agnostic regarding the choices that a patient might wish to make at the end of life. Rather, it simply sought to provide reimbursement for, and thus encourage, the often lengthy and difficult conversations between physicians and ailing patients about the sort of care that the patient would like to receive in the event of further declining health. However, it is no secret that care provided at the end of life can be very expensive. Indeed, over twenty-five percent of Medicare dollars are directed toward beneficiaries in their last year of life, despite the fact that many of these medical expenditures may not improve health outcomes.²³ When opponents coupled this with the Affordable Care Act's stated emphasis on cost-containment, even though that emphasis had nothing to do with the ACPC, the conclusion the opponents were pushing may appear more plausible—namely, that saving money at the expense of vulnerable patients' lives had, in fact, become the proverbial cake.

A majority of ACPC opponents, especially those who disseminated some of the most damaging rhetoric (e.g., former Alaska Governor Sarah Palin and House Republican Leader John Boehner), claim to support smaller government expenditures on most social items.²⁴ Therefore, it may seem odd that they so vehemently opposed a measure that they claimed was intended to reduce government spending. Their negative reaction, however, may have been a result of their

equating cost reduction with healthcare “rationing” and government regulation that could “hasten death.” As Jonathan Oberlander and Joseph White observe, “There is good evidence that many Americans oppose reform if it means reduced access to medical care. The public is eager for cost controls that limit their rising medical bills, not for restrictions on the availability of services. That makes any reform proposal vulnerable.”²⁵ Comparative effectiveness research is one major target of such suspicions along with end-of-life care, so, in an attempt to assuage fears that provisions under ACPC might encourage government panels to regulate or monitor physicians’ decisions, supporters of the legislation pointed to Section 1401 of H.R. 3200, which stated that “[n]othing in this section shall be construed to permit the Commission or Center [for Comparative Effectiveness Research] to mandate coverage, reimbursement, or other policies for any public or private payer.”²⁶ Others, including Representative Blumenauer, who sponsored legislation similar to § 1233 prior to the 2009 health reform debate, noted that the section was simply furthering an ongoing, bipartisan effort to inform people of their medical choices at the end of life, and that nothing in the legislation or elsewhere sought to encourage people to make any particular decision regarding such care.²⁷

Despite presenting such arguments and drawing attention to the text of §1233 specifically—which includes no references to rationing or exclusions of coverage—supporters of the ACPC were unable to dispel myths surrounding it. Two polls conducted just one month after the proposal was introduced indicated that approximately thirty percent of the American public believed “death panels” were included in the bill and were being considered by lawmakers.²⁸ More disturbingly, a Kaiser Health Tracking Poll conducted in March, 2013, found that, three years after the ACA’s enactment, forty percent of the American public believes the ACA contains a “death panel” provision.²⁹ The opponents’ rhetoric concerning regulation, rationing,

and poor health outcomes continues to influence public opinion surrounding healthcare reform, even after the fact. Indeed, public opinion experts often view the kind of negative rhetoric directed at federally funded comparative effectiveness research “as a winning line of attack on health reform precisely because it arouses the public’s suspicions.”³⁰

Where §1233 May Have Gone Wrong

Much if not most of the hyperbolic rhetoric surrounding §1233 was untrue and inappropriate, yet it made a significant impact on public opinion. It is important that we begin to understand what may have incited opponents to make these claims. Although the stated goal of the ACPC supporters was to inform patients of their treatment options at the end of life, opponents argued that the actual goal of the ACPC was to reduce Medicare spending via government regulation. Although much of the discourse surrounding cost-efficiency and regulation was exaggerated and inaccurate, a closer look at some of the language in §1233 may reveal why it was interpreted as being primarily focused on cost-savings and why opponents of the measure were able to influence some of the American public to draw this conclusion.

The proposed language in the ACPC subsection would have made engaging in end-of-life consultations completely voluntary. However, as noted above, the consultation itself would have needed to include “mandatory content” in order for the healthcare provider to be reimbursed under Medicare.³¹ Some of this mandatory content included an explanation of advance care planning, advance care directives, living wills, and durable powers of attorney; an explanation of the role and responsibilities of a healthcare proxy; the provision of a list of national and state-specific resources to assist in advance care planning; an explanation of the continuum of end-of-life resources available including palliative and hospice care; and an explanation of orders regarding life-sustaining treatment, including why such orders are beneficial to the individual

and the family.³² There is nothing inherently wrong with this mandatory content. However, a mandate to cover all of these areas would have the potential to create a very structured consultation that would provide little room for genuine dialogue and listening.

Take, for example, one study that found physicians spoke twice as much as they listened during outpatient advance directive consultations and rarely inquired about patient values or feelings of uncertainty.³³ If this is the case for routine conversations concerning advance care directives, it may be that highly structured consultations, as directed by §1233, would only exacerbate these problems. What is more, leading a structured consultation with the intent of satisfying explicit requirements within the conventional time limitations of an office visit may inhibit a physician from adequately addressing all of the patient's concerns, especially considering that discussions about end-of-life care can be an emotional experience fraught with fear, grief, worry, and indecision. Researchers suggest that a "checklist" approach to advance care planning will not meet patients' needs and that "determining a preference is not the same as looking up a fact, such as stepping on a scale to learn one's precise weight ... [a] preference for something as complex and emotionally charged as end-of-life care depends on a process of discussion and feedback within the network of relationships that are meaningful to a person."³⁴ Engaging in this kind of open-ended dialogue would be difficult if a physician were required to include all of the mandatory content listed in §1233.

Additionally, some critics took issue with the imperative that doctors "report back" to the government the outcome of the end-of-life consultation.³⁵ Although, as mentioned above, §1401 of H.R. 3200 provided that the recommendations of the Comparative Effectiveness Research Commission could not be interpreted as mandates or guidelines for payments, some critics were uncomfortable with §1233's proposition to amend §1848(k)(2) of the Social Security Act and

expand the “Physician Quality Reporting Initiative” to include “measures on quality end-of-life care” that would assess “both the creation and adherence to orders for life-sustaining treatment.”³⁶ Though these quality measures did not appear to be linked in any way to physician reimbursement, some were wary of the potential monitoring of physicians’ adherence to end-of-life decisions made with their patients. A fear was that the “quality” of a physician’s end-of-life consultation would be determined by a patient’s decision to limit aggressive care at the end of life and then adhere to this decision.³⁷ If this were the case, then perhaps a physician would pressure a patient to limit care and then follow through with this decision, even if the patient later changed his or her mind.

This fear, however unfounded it may have been, might have resulted from the fact that §1233 was born into a political environment dominated by healthcare reform and cost controls. Senator Grassley, in implying a connection between reimbursement for discussions about end-of-life care and healthcare cost reduction, provided a rational face for the irrational hysteria over the ACPC. As Eugene Robinson of the *Washington Post* put it:

[R]eform is being sold not just as a moral obligation but also as a way to control rising healthcare costs. ... We perform more expensive tests, questionable surgeries, and high-tech diagnostic scans than we can afford. We spend unsustainable amounts of money on patients during the final year of life. ... That’s why people are so frightened and enraged at a measure that will allow Medicare to pay for end-of-life counseling. If the government says it has to control healthcare costs and then offers to pay doctors to give advice about hospice care, citizens are not delusional to conclude that the goal is to reduce end-of-life spending.³⁸

Considering that nearly thirty percent of Medicare’s annual costs are attributable to beneficiaries in their last year of life,³⁹ one might surmise that the government would wish to reasonably reduce costs, especially for futile treatments at the end of life; yet, Robinson suggests our moral obligations at the end of life (e.g., limiting suffering or invasive treatments) “should have been a separate discussion” from controlling rising healthcare costs.⁴⁰ Others, however, maintain that

with our rapidly aging United States population and our finite amount of healthcare resources, it is impossible to untangle cost considerations and ethical considerations when creating policy about end-of-life care.⁴¹ If it is true that these two discourses cannot, in fact, be disentangled, how do we address the fact that people become “frightened and enraged” when they feel the government has taken end-of-life conversations—conversations that should be patient-centered and focused on ensuring quality care at the end of life—and promoted them in the alleged name of cost-reduction?

Moving Forward: A Reevaluation of Goals

If we are ever to make progress toward creating policy that incentivizes physicians to engage in constructive end-of-life conversations, we need to do so in a way that appeals to the shared values of those across the political spectrum. Deborah Stone observes that the “first task of the political analyst is to reveal and clarify the underlying value disputes so that people can see where they differ and move toward some reconciliation.”⁴² Despite polarizing rhetoric and conflicting interpretations of the ACPC, one would be hard-pressed to find anyone from either side of the political spectrum who would deny that terminally-ill patients should be able to talk with their physicians about their prognosis, make their wishes known, and to die a “good death.” Even healthcare policy commentator Betsey McCaughey, who may have been ACPC’s most tenacious adversary, said, “I believe in advance [care] consultations ... it is one thing to pay doctors to spend time with their patients discussing this issue. I am not against this. But putting pressure on doctors to require patients to go through a consultation that’s prescribed by the government and then to penalize [physicians] if the patient or their family changes their mind ... that’s really wrong.”⁴³ Although McCaughey’s reading of the provision was inaccurate, her statement does indicate that she was not opposed to physicians engaging in end-of-life

conversations, per se. Rather, her critique developed in response to perceived “government prescribed” consultations and to the potential assessment of patient-adherence and cost-effectiveness. It seems, then, that in order to garner greater support, any healthcare reform policy about end-of-life care needs to emphasize what appears to be a shared and virtually uncontested value of engaging in open, genuine dialogue about end-of-life care and focus less on mandatory content, cost-efficiency, and adherence.

Although §1233 had the potential to catalyze physician-initiated end-of-life conversations, the shared value of genuine conversation and patient-centered care at the end of life was obscured by structured consultations and mandatory reports to government agencies. These mandates seemed to shift the goal of the consultation from open and honest dialogue to obtaining advance care directives that could potentially put limits on expensive treatments during a patient’s final days, even though the creation or amendment of such a directive or other order concerning life-sustaining treatment was not proposed as a requirement for payment under the section. Although limiting expensive and ineffectual treatment is important, one must note that advance care directives alone may not lead to significantly improved care or reduced costs at the end of life.⁴⁴ Simply signing an advance care document does nothing, on its own, to foster patient-provider communication concerning end-of-life care, and patient preferences may change when actually faced with a terminal illness. In light of this, researchers have suggested that advance care planning should focus more on improving communication between patients, their loved ones, and providers, and less on completing documents, as “documentation alone is unlikely to improve outcomes.”⁴⁵ This kind of planning requires real listening on the part of the physician and a conversation (or multiple conversations) that addresses a patient’s values, preferences, concerns, and feelings of fear and uncertainty. As Timothy Quill notes, end-of-life

discussions need to move beyond simply creating a treatment plan and begin to address “issues of life closure.”⁴⁶ If this does not happen, desires like writing memoirs, attending a child’s wedding, and ensuring that one dies at home with his or her family may be left unfulfilled.

Quill goes on to say that although the ultimate goal of these conversations is not simply to obtain documentation of treatment decisions, it is often the case that open-ended conversations that explore patient goals, values, and expectations naturally lead to decisions about specific end-of-life treatment.⁴⁷ Thus, conversations like these, when facilitated well, have the potential not only to address patients’ fears, anxieties, and issues of life closure, but also to lead to better care and more cost-effective treatment at the end-of-life—one of the reasons the ACPC was proposed in the first place.

However, the problem remains that end-of-life conversations are not happening often enough. These conversations are very difficult to have, as they often involve confronting emotion, contending with the reality of a terminal diagnosis and death, and making difficult decisions. As such, patients near the end of life may avoid these conversations in an attempt to protect themselves and their loved ones from pain. Physicians, too, may avoid initiating these conversations because they are uncomfortable addressing difficult emotions or are fearful that acknowledging the inevitable will lead to a patient’s sense of “hopelessness.”⁴⁸ In fact, physicians may offer new lines of treatment, even after multiple therapeutic failures, as a means of circumventing difficult discussions of prognosis or advance directives.⁴⁹ As a result, “each party is waiting for the other to begin the conversation,” which can result in unwanted treatment and a significant delay in hospice care.⁵⁰

Research suggests that receiving aggressive life-sustaining treatment at the end of life—including cardiopulmonary resuscitation, artificial nutrition and hydration, and intubation—may

be ineffectual, increase patient discomfort and distress, and lead to greater suffering, thus preventing a “good death.”⁵¹ Craig Earle and colleagues, focusing on terminally-ill cancer patients, identified factors that may indicate when patients have received poor end-of-life care. These factors include frequent emergency room visits or hospitalizations near the end of life, being referred to hospice too late or not at all (and thus dying in an acute-care setting), and continuing with or initiating new anticancer therapies very near death.⁵² These factors may not only prevent a good death for a patient, but they may also bring harm to a patient’s loved ones. Family members who participated in focus groups for this study stated that because their loved ones were still receiving treatment very late in the disease trajectory, they were unaware of just how advanced the disease was. As a result, “their loved one’s death was an unexpected shock.”⁵³ Moreover, when patients receive unwanted care such as resuscitation or intubation, family members may be needlessly faced with painful decisions regarding extubation or cessation of artificial hydration and nutrition. As Steinhauser and colleagues note, “Too frequently in medicine, a crisis arrives in the absence of forethought. As a result, patients’ wishes may not be known, family members are confused about choices, and healthcare providers may find themselves engaged in interventions perceived as futile.”⁵⁴ It is unlikely that this kind of crisis would ultimately lead to what we might describe as a “good death.” Thus, it is imperative that we prevent this “absence of forethought” by engaging in open and honest dialogue about death and dying before the crisis ever presents itself.

Healthcare practitioners are less likely to initiate end-of-life conversations when they feel they lack the interpersonal skills required to do so.⁵⁵ Dale Larson and Daniel Tobin suggest that topics surrounding end-of-life conversations and the interpersonal skills required to engage in such conversations receive too little attention, despite the fact that the “emotional and time

demands of these discussions” need to be addressed.⁵⁶ Thus, they propose that healthcare practitioners would benefit from additional training in this area, and they highlight several existing training programs that focus on fostering communication skills, active listening, and empathy that have shown to effectively improve patient outcomes. Data from several studies suggests that facilitating such a program regionally, targeting both healthcare providers and the general public, can yield significant increases in both the drafting of advance care directives by patients and the likelihood that a patient’s wishes regarding end-of-life care will be followed.⁵⁷

While there is ample literature that physician sub-specialists could use to improve their communication and empathy skills with respect to patients facing terminal conditions,⁵⁸ improved communication may be furthered if each patient has a designated individual who is in charge of managing the patient’s care. In many areas of the United States, patients with complex terminal conditions may have multiple physicians, not one of whom may be responsible for overall coordination of care.⁵⁹ In such situations, it may be more likely for physicians to avoid difficult discussions about end-of-life care that are not presently considered a “routine” part of caring for a patient. While it may be that multiple different providers with different expertise will be necessary for a complete discussion of a patient’s options, healthcare systems in which patients have a designated care coordinator and improved integration have shown better outcomes in not only having advance care discussions but also in increasing the use of hospice care and in reducing in-hospital deaths.⁶⁰ Better-coordinated care of the sort envisioned through the use of accountable care organizations and patient-centered medical homes, as supported by the Affordable Care Act, may offer improved opportunities to facilitate thoughtful and constructive end-of-life planning.

Better incentives, both for education and consultation, may also increase the number of patients who receive appropriate and timely discussion regarding their options at the end of life. If our goal is to promote authentic dialogue about death and dying that moves beyond documentation and begins to address patient concerns and values, then we ought not reimburse physicians for simply explaining advance directive forms and treatment options—as proposed in §1233—but should instead seek to encourage more open conversations and train physicians to facilitate them well. Moreover, because these conversations are much less structured than those proposed under the ACPC, physician reimbursement would need to be contingent on something other than proving that mandatory content was addressed or that actionable medical orders were obtained. Instead, physicians might be reimbursed using existing or newly-devised Medicare payment codes for other open-ended face-to-face encounters, such as those currently used for time spent in “patient education and counseling.”⁶¹

The amended ACPC provision that the House (but not the Senate) ultimately passed could act, and has acted, as a model in this regard. Unlike the original version that caused the furor, the amended ACPC made the content of reimbursable discussions between healthcare providers and patients permissive rather than mandatory, and left it up to the regulatory process to fill in further details. While the permissiveness initially may look promising, giving the Secretary of Health and Human Services such discretion in determining the ultimate requirements for a reimbursable advance care planning consultation may not strengthen the bill’s chances. Rather, as mentioned above, it would be advisable to clearly state in the law that the content of advance care planning conversations should emphasize patient need over formalistic box-checking. Templates for this already exist. Instead of using reimbursement for standard evaluation and management services as a guideline—in which providers are reimbursed more for

including a greater number of physical examination elements— it may make more sense to mirror reimbursement for services such as patient education, health and behavior intervention, telephone evaluation and management, or psychotherapy , in which providers are reimbursed based on time rather than content.⁶² The need to assure good content could be addressed through education on thoughtful end-of-life planning for both health care providers and patients. Because these consultations would not be “regulated” and physicians would not have to show evidence of having addressed any specific content, medical schools, hospitals, clinics, and professional societies should emphasize and incentivize quality training in end-of-life planning so as to ensure that these consultations are carried out well.

Unlike the original ACPC, the amended ACPC got a number of other issues right. It expressly provided that “[n]othing in this section shall require an individual to complete an advance directive, an order for life sustaining treatment, or other advance care planning document; [or] require an individual to consent to restrictions on the amount, duration, or scope of medical benefits an individual is entitled to receive under this title.”⁶³ It additionally omitted the reporting requirements that existed in the original version. Representative Earl Blumenauer of Oregon, the original sponsor of the ACPC prior to the introduction of the Affordable Care Act, has continued to sponsor bills resembling the amended ACPC, most recently in 2011.⁶⁴ In this subsequent legislation, he and his co-sponsors have included findings of fact, emphasizing the benefits of educated patient discussion and choices concerning the care patients receive in their final months. The 2011 iteration of the bill includes advance care planning as a benefit not only for Medicare but also Medicaid patients.⁶⁵ It would also provide grants to fund the establishment or expansion of statewide programs for physician orders regarding life-sustaining

treatment, establish advance planning standards for electronic medical records, and provide for the portability of advance directives from state to state.⁶⁶

The most recent iteration of Rep. Blumenauer's bill was tabled, but deserves more serious and sustained consideration. Discussions concerning end-of-life care are time-consuming and difficult. Yet they can, in their own way, be fulfilling for providers, patients, and patients' families.⁶⁷ We should underscore to physicians that we as a society find such conversations, no matter what their outcome, worthwhile and necessary by providing monetary reimbursement for them. As we move farther from the damaging rhetoric of the battle over healthcare reform, and as legislators such as Rep. Blumenauer continue to propose thoughtful bills, perhaps we can eventually achieve this end.

Conclusion

Considering that most patients believe it is their physician's responsibility to initiate end-of-life discussions, and given the fiduciary nature of the patient-provider relationship, the responsibility of initiating end-of-life conversations ultimately falls in the hands of the physician.⁶⁸ Some experts suggest that helping a patient make the transition into palliative or hospice care could be made easier if therapies for symptom control were combined with curative therapies early on in the disease trajectory. This would require a "paradigm shift" of sorts, as the individual sphere of palliative care would need to intersect with the distinctly curative sphere that tends to dominate mainstream medical care in America.⁶⁹ If a conversation about palliative care is initiated at the frontend of a patient's treatment plan, end-of-life transitions may be easier to discuss if and when the patient reaches that point.

Even if palliative care is introduced alongside traditional therapies, however, any conversation concerning end-of-life care has the potential to be emotionally difficult and time-

consuming for the physician. Therefore, finding a way to incentivize healthcare providers to initiate these conversations is a critical issue. Although the financial incentive for addressing end-of-life issues outlined in §1233 was a good start, the provision ultimately fell short because it failed to explicitly reflect the fundamental goal of end-of-life planning: engaging in important, albeit difficult, conversations about end-of-life issues that can create a space in which patients may begin to acknowledge the inevitable, make appropriate decisions for their end-of-life care, and die in as much comfort and with as much dignity as possible. Policymakers' original intent may have been to foster real dialogue about end-of-life care that could lead to a good death, yet this goal was inevitably muddied by mandates for a structured consultation primarily focused on obtaining advance care documentation. As Daniel Callahan observes: "A perennial problem seems to be the American temperament, which is much more comfortable in fashioning health policy, or any kind of policy, using the language of management techniques and economic efficiency ... than with the articulation of clear healthcare goals."⁷⁰ Though "economic efficiency" may be a valid concern in end-of-life care, we cannot allow it, if considered, to obscure what should be our primary goal—namely, promoting authentic dialogue between physicians, patients, and family members that can lead to emotional support and patient-centered care at the end of life.

If we determine that cost-effectiveness and ethical considerations are inextricably connected within the context of end-of-life care, then we must ask ourselves which of these considerations is our primary concern. The primary concern of both the American people and our lawmakers ought to be to ensure patient-centered care at the end of life. Our policymakers should work toward preventing what happened with N.P.'s mother from happening to other families with dying loved ones. Their ultimate goal should not be to simply save money but to prevent the

serious physical, emotional, and financial problems that can result when patients, family members, and physicians deny the inevitable. Any policy created to incentivize physicians to engage in end-of-life conversations needs to speak clearly to these values in order to garner support from across the political spectrum.

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