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NOTES AND COMMENTS

Quality Measurements, Payment, and the Law: Disincentives to Physician-Patient Discussions of End-of-Life Care

Harvey M. Tettlebaum

ABSTRACT: With passage of the Affordable Care Act, the government is playing a dramatically increasing role in not only payment for healthcare but also the standards by which care is delivered. Therefore, it is important that the disincentives to patient discussions of end-of-life care in the laws and regulations, and the mechanisms used to enforce both, be well understood to avoid in the future what has occurred in the past.

KEYWORDS: End-of-Life, Hospice, Advance Directives, Death-Denying Culture, Patient Self-Determination Act, Affordable Care Act

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Tettlebaum: Disincentives to End-of-Life Discussions

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Introduction

It is the twenty-third anniversary of the enactment of the Patient Self-Determination Act (PSDA), which is part of the Omnibus Budget Reconciliation Act of 1990.¹ It applies to hospitals, nursing facilities, home health agencies, hospice programs, and other organizations. The PSDA requires that providers give information to persons receiving care about their rights under state statutory or case law, to allow them to make decisions concerning their medical care, including their right to accept or refuse treatment and their right to formulate advance directives. It also contains provisions regarding the healthcare organization’s documentation of compliance with the statute. The PSDA was designed, in part, to give patients the rights to refuse treatment and to designate their wishes in advance to avoid situations such as arose with Nancy Cruzan and Terri Schiavo. If its success is measured by the number of Americans who have advance directives, then it has not accomplished its goal completely.²

In 2009, Congress proposed Section 1233 of the Health Care Reform legislation that, not unlike the PSDA, required practitioners to provide an explanation of advance directives, healthcare proxies, advance care planning, and information regarding palliative care.³ Section 1233 further required advance care planning consultations in certain situations including “diagnosis of a chronic, progressive, life-limiting disease, a life-threatening or terminal diagnosis or life-limiting injury, or upon admission to a skilled nursing facility, a long-term care facility [], or a hospice program.”⁴ It further provided for development of orders “regarding life sustaining treatment” during that consultation, to enable the patient to provide his or her preferences. It specified the

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³ H.R. 3200, 111th Cong. § 1233.
⁴ Id.
levels of treatment that could be indicated regarding life-sustaining treatment.\footnote{Id.}

The adoption of that provision was scuttled by the controversy created from its characterization by former governor Sarah Palin as “death panels.” Governor Palin’s actions also may have prevented a fuller discussion of the cultural issues that have evolved over the past 47 years about the role of death as part of life and its place in the healthcare continuum. This Comment will discuss the impediments from existing quality measurements and payment structures to discussions by physicians with their patients about end-of-life issues. Without those discussions, a more dispassionate and analytical debate cannot occur within our society to bring about a change in our death-denying culture.

**Shortcomings of the Patient Self-Determination Act**

The PSDA took effect in 1991. Its goal was to alert individuals to their right under state law to have an advance directive to designate what healthcare they preferred, especially at the end of life, and also to inform them of their right to a surrogate to assist them in making healthcare decisions if and when their condition did not permit them to do so. The PSDA grew out of the situation involving Nancy Cruzan. Its principal sponsor in Congress, Missouri’s Senator John C. Danforth, was well aware of the circumstances surrounding the Cruzan case.\footnote{See Cruzan v. Dir., Mo. Dep’t of Health, 497 U.S. 261 (1990). Cruzan was in a persistent vegetative state. Id. at 266. Her parents sought to have her artificial nutrition and hydration terminated. Id. at 267. Missouri statute required clear and convincing evidence of the patient’s wishes before it would permit another person to order the termination of medical treatment. Id. at 268-69. The only evidence of Cruzan’s wishes was her statement to a roommate that she would not want to live as a “vegetable.” Id. The Missouri Supreme Court held that the evidence of Cruzan’s wishes was insufficient. Id. The United States Supreme Court affirmed, thereby approving Missouri’s use of the clear and convincing evidence standard as a balance between an individual’s right to refuse treatment and the State’s interest in preservation of human life. Id. at 287.} Senator Danforth hoped that the PSDA would offer the least intrusive method to encourage individuals receiving services paid for by government third-party payors to engage in some type of health and
end-of-life planning. He also hoped that it would avoid a repeat of the Cruzan situation and encourage people to take personal responsibility for making choices about the type of care they did or did not want and for appointing the person to act as their healthcare surrogate in the event they were unable to make those decisions.

As Leahman points out, only 30% of Americans have advance directives. In addition, although patients and their families prefer to die at home, as of 2004, four of five deaths in the United States take place in hospitals and nursing homes. Leahman notes that the PSDA’s emphasis is on documents rather than conversation. Because no one likes to talk about death, those conversations rarely occur even though some studies show that patients want honest answers from their physicians, with 88% wanting to understand treatment options and 74% fearing to die painfully. Only 11% of patients, however, have expressed their concerns to their physicians.

**Impediments to End-of-Life Discussions**

Over the years with advent of increasingly broader coverage of healthcare services and items from both private and public sources, life expectancy has increased, which has caused a change in perception and belief about the expectancy of death. These factors, along with outdated hospice regulations and subjective or inappropriate enforcement of quality standards in long term care settings, have created impediments to end-of-life discussions.

**The culture of life and death**

Because the Medicare program’s goal has been thoroughly discussed during its 48 years, we do not need to dwell on it here. However, we must consider the consequences of the infusion of hundreds of

7 Leahman, at 249.
8 Id.
9 Id. at 250.
10 Id.
11 Id.
millions of dollars into the healthcare system, including the development of sophisticated diagnostic and treatment technology together with advancements in durable medical equipment and the very concepts of what the healthcare system can accomplish. As a result, life expectancy has increased substantially; but more importantly, Americans’ expectations about their ability to survive what previously were fatal conditions or injuries have created a death-denying culture within the United States.

All Americans know that they will die; they just do not believe they will do so very soon. Life can be extended by organ transplants, replacements of other body parts with artificial ones, or medications that provide seemingly miraculous cures. Those expectations have fueled a healthcare industry that is the envy of the world. However, it also has fueled a legal system that takes advantage of expectations to recover large sums of money in malpractice litigation based on outcomes that result either in death or increased morbidity but characterized in lawsuits as unnecessary or avoidable. This has produced a medical-legal complex that has made it difficult for providers and patients to engage in frank and honest discussions about their healthcare.

Physicians

Several years after the PSDA’s enactment, Dr. Summers found that:

Many clinicians consider a “good patient” to be one who does what they suggest with a minimum of interference. Patients who want to take a more active role in their own treatment can take more physician time than passive patients. They may want better explanations of what treatments have been ordered for them and why. In spite of the extra time needed to answer

12 This is gleaned from the author’s and his law firm’s extensive experience defending healthcare providers in hundreds of malpractice cases.
questions, benefits accrue to the organization from treating adult patients, and parents of sick or injured children, like the adults they are.\textsuperscript{13}

Dr. Summers quoted the 1980s’ President’s Commission for the Study of Bioethical Problems in Medicine that found that patients who were more involved in the decision-making about their treatment:

- recovered more rapidly;
- reported less pain and needed less pain medication;
- were no more likely to report having any of the side effects or complications described to them about their treatment, but were more likely to identify their side effects or complications as one of those described; and
- were less likely to file a malpractice claim if the negative side effects or complications took place.\textsuperscript{14}

Dr. Atul Gawande describes this situation well.\textsuperscript{15} As he points out, physicians are neither trained to engage in these discussions nor comfortable doing so; however, he found that patients appreciate this discussion and usually make sound decisions as a result of the information provided.\textsuperscript{16}

A number of articles illustrate the cost to society and patients in terms of both quality of life and dollars stemming from the lack of physician-patient discussion. The Dartmouth Institute for Health Policy & Clinical Practice, as part of its Atlas Project, recently published \textit{Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe

\begin{thebibliography}{9}
\bibitem{14} \textit{Id.}
\bibitem{16} \textit{Id.}
\end{thebibliography}
Chronic Illnesses. The study supports the use of palliative and hospice care and physicians’ conversations with patients to determine the care that patients really want to receive. The report notes:

Regions and hospitals with high-intensity patterns of care for patients with serious chronic illness have been found to have high hospital and specialist utilization rates in the first year after a heart attack; more aggressive care for patients with advance cancer who are near the end of life; and higher readmission and hospitalization rates for potentially avoidable causes of hospitalization.18

The report states that the “greater amount of hospice care is accompanied by a decrease in the cost of end-of-life care.”19 It explains that the variations found in the treatment of chronically ill Medicare patients may depend largely on the “systems of care within different regions and hospitals.”20 The prevalence of physician-patient conversations about end-of-life issues is part of that variation.

Payment structures and systems

Medicare payment systems have favored “high-tech, hospital-based care.”21 They have been less generous for “high touch” treatment.22 With all of this technology available to care for patients at the end of their life, and the public believing “death is the enemy,” physicians tend to be “aggressive,” expressing enthusiasm for technology.23

18 Id. at 3 (citations omitted).
19 Id. at 12 (citations omitted).
20 Id. at 33.
22 Id.
23 Id.
Impediments to End-of-Life Discussions

The statistics best demonstrate the effects of both the Medicare payment system and our current culture. In the 2007 data (the last year of its availability), 28.1% of all decedents died in the hospital, 17.6% probably spent time in an intensive care unit, and the actual days spent in the hospital during the final six months of life averaged 10.9%. A recent study of 1.8 million Medicare enrollees over the age of 65 who died in 2008 showed that 31.9% had a surgical procedure in their last year of life, 18.3% had a surgical procedure in the last month of life, and 8% had a surgical procedure in the last week of life. Even for persons in their 80s, 23.6% had an operation in their final year of life.

Although most patients would prefer to die at home, the Medicare payments available for home healthcare and hospice are not sufficient to meet a dying person’s needs and deal with the pain, breathing issues, gastrointestinal issues, and necessary medication administration. Approximately 15% of hospice patients disenroll and transfer to an acute care hospital for their healthcare needs.

Medicare also has changed the prevalence of the conditions from which we die. During the last century, chronic diseases displaced infectious diseases and injury as the leading causes of death. For example, in 1900 the number one cause of death was pneumonia. In 2000, it was heart disease. The number two cause of death in 1900 was tuberculosis. In 2000, it was cancer. Although the age of death in 1900 was 47, in 2000 it was 75. In 1900, the usual place of death was a person’s home. In 2000, it is more likely the hospital. Of course, in 1900 the

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24 Id. at 36.
25 Alvin C. Kwok et al., The Intensity and Variation of Surgical Care at the End of Life: A Retrospective Cohort Study, 378 LANCET 1408, 1410 (2011).
26 Id. at 1411.
family covered the medical expenses; whereas in 2000, Medicare covered most medical expenses. In 1900, there was not as much disability before death; whereas in 2000 the average disability before death was two years.\textsuperscript{29}

The population demographics are well known. The number of people over age 85 will double to 10 million by 2030.\textsuperscript{30} 23\% of Medicare patients with over 4 chronic conditions account for 68\% of all Medicare spending.\textsuperscript{31} 10\% of Medicare beneficiaries have over 5 chronic conditions and drive two-thirds of Medicare spending.\textsuperscript{32} 95\% of all healthcare spending is for the chronically ill.\textsuperscript{33}

In the healthcare marketplace, most healthcare systems pay providers for procedures, chemotherapy, clinical visits, and emergency room visits as opposed to caregiving, communication, pain control, home visits, or 24-hour on-call nursing. Although hospice and other palliative care programs have grown dramatically in the past decade, payment limitations make full integration of these programs difficult. For example, a person entering Medicare hospice relinquishes the right to Medicare payment for direct care.

\textbf{Hospice audits and enforcement}

Recent studies have shown that enforcement efforts affect physician conduct when deciding to advise and treat their patients. For a Medicare patient to be eligible for the hospice benefit, he or she must obtain physician certification of a prognosis that the patient will die in six months.\textsuperscript{34} This certification requirement can be the most difficult to satisfy.

\begin{itemize}
\item \textsuperscript{29} Id.
\item \textsuperscript{30} Id.
\item \textsuperscript{31} Id.
\item \textsuperscript{32} Id.
\item \textsuperscript{33} Id. For a fuller discussion, see also \textit{John E. Wennberg et al., Dartmouth Inst. for Health Policy \& Clinical Practice, Tracking the Care of Patients with Severe Chronic Illness} 21–37 (2008), available at \url{www.dartmouthatlas.org/downloads/atlases/2008_Chronic_Care_Atlas.pdf}.
\item \textsuperscript{34} 42 C.F.R. § 418.20; see also Ctrs. for Medicare \& Medicaid Servs., Medicare Hospice Benefits 4 (2013), available at \url{www.medicare.gov/publications/pubs/pdf/02154.pdf}.
\end{itemize}
According to the Medicare Benefit Policy Manual, Chapter 9 (Cover-
age of Hospice Services Under Hospital Insurance), Section 1814(a)(7)
of the Social Security Act specifies that certification of terminal illness
for hospice benefits shall be based on the clinical judgment of the
hospice medical director or physician member of the interdisciplin-
ary group (IDG) and the individual’s attending physician, if he or she
has one, regarding the normal course of the individual’s illness.35 No
one other than a medical doctor or doctor of osteopathy can certify
or recertify a terminal illness.36 The attending physician is a doctor
of medicine or osteopathy or a nurse practitioner and is identified by
the individual, at the time he or she elects to receive hospice care, as
having the most significant role in the determination and delivery of
the individual’s medical care. For the first 90-day period of hospice cov-
erage, the hospice must obtain, no later than two calendar days after
hospice care is initiated (by the end of the third day), oral or written
certification of the terminal illness.37

For subsequent periods, the hospice must obtain, no later than two
calendar days after the first day of each period, a written recertification
statement from the medical director of the hospice or the physician
member of the hospice’s IDG.38 Additionally, for recertifications on or
after January 1, 2011, a hospice physician or hospice nurse practitioner
must have a face-to-face encounter with each hospice patient prior to
the beginning of the patient’s third benefit period, and prior to each
subsequent benefit period.39 Failing to meet the face-to-face encounter
requirements specified in this section results in a failure by the hos-

35 CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE BENEFIT POLICY MANUAL CH. 9 – COVERAGE OF
HOSPICE SERVICES UNDER HOSPITAL INSURANCE § 10 (REV. 156, 06-01-12), AVAILABLE AT WWW.CMS.
GOV/REGULATIONS-AND-GUIDANCE/GUIDANCE/Manuals/Downloads/bp102c09.pdf; 42
C.F.R. § 418.102(b).
36 See supra note 35.
37 42 C.F.R. §§ 418.22, 428.25.
38 Id.
39 Patient Protection and Affordable Care Act, § 3132(b)(2)(D), 42 U.S.C. § 1395f(a)(7)(D);
42 C.F.R.§ 418.22(a)(4).
pice to meet the patient’s recertification of terminal illness eligibility requirement. The patient would cease to be eligible for the benefit.\textsuperscript{40}

The evidentiary burden of certifying and then frequently recertifying that an individual is suffering from a terminal illness and the limitation on who may corroborate the terminal nature of an illness for purposes of Medicare coverage favor the conclusion that election of hospice care over other forms of more aggressive medical intervention is discouraged under the Medicare program. These barriers are of particular concern where patients are unable to access certain medical professionals, either because of their regional location or economic situations, or because their care has been disjointed and not delivered consistently by one particular attending physician.

As the number of persons enrolling in the Medicare Hospice Program has increased, the government has increased its audit of hospice providers. Except for cancer patients, persons suffering from other conditions commonly seen in hospice, such as dementia or heart disease, have a dying process that is more difficult for physicians to predict.\textsuperscript{41} The inability to predict the decline in the health of patients with non-cancer illnesses conflicts with the six-month certification requirement.\textsuperscript{42} Although the National Hospice Organization has guidelines for physicians to use when making certifications of a terminal illness, hospice treatment can alleviate many disease symptoms, further extending the need for hospice care and calling into question the initial certification decision.\textsuperscript{43}

Studies have shown that the National Hospice Organization guidelines have prevented persons otherwise qualified with certain conditions for hospice from benefitting from that care modality.\textsuperscript{44} Other studies

\begin{itemize}
\item \textsuperscript{40} See supra note 39.
\item \textsuperscript{42} \textit{Id.} at 196.
\item \textsuperscript{43} \textit{Id.} at 197–99.
\item \textsuperscript{44} \textit{Id.} at 200.
\end{itemize}
show that the degree of accuracy required for the six-month certification creates a standard so difficult that treating physicians are unable to meet it.\textsuperscript{45} As the hospice benefit became more commonly used and the number of Medicare beneficiaries accessing it grew substantially, the government began audit and enforcement procedures to detect and eliminate fraud in its provision. This started in the mid-1990s with Operation Restore Trust during the Clinton Administration\textsuperscript{46} and continues to this day.

Experts believe that both patients and physicians delay enrollment in hospice because they are reluctant to accept the inevitability of death by ending treatment, unfamiliar with end-of-life options, and hampered by the “chilling effect of a federal Medicare fraud probe.”\textsuperscript{47} The Operation Restore Trust audits, investigations, and prosecutions uncovered cases of fraud by organizations, resulting in heavy penalties, because patients outlived the six-month prognosis.\textsuperscript{48} As the National Hospice Organization guidelines have been subject to more critical review, physicians increasingly have relied on their own clinical judgment to determine the basis for a six-month prognosis.\textsuperscript{49} This judgment subjects them to potential fraud audits and investigations, creating a “chilling” effect that can prevent patients who would otherwise need hospice from eligibility certification.\textsuperscript{50} Physicians perceiving a threat of an audit or investigation concerning their certification of a patient’s terminal status are reluctant to even discuss the option with their patients, due to the potential that it could trigger government oversight of their decisions.\textsuperscript{51}

\textsuperscript{45} Id.  
\textsuperscript{46} Id. at 188–89.  
\textsuperscript{47} Id. at 204 (quotation and citation omitted).  
\textsuperscript{48} Id. at 205.  
\textsuperscript{49} Id. at 212.  
\textsuperscript{50} Id. at 212–13.  
\textsuperscript{51} Id. at 214.
Other regulatory standards and administrative enforcement

The government’s regulatory policies can maintain and even reinforce our society’s death-denying culture. This includes hospice regulatory requirements,52 long-term care facility certification, and compliance standards (see further below).53 Even for end-of-life care provided in a nursing home—a common site for such care—the current quality measures are based on the minimum data set, which focuses on restoration and maintenance of functioning and does not include indicators appropriate to end-of-life care.54 The quality measures in nursing homes, such as functional decline, weight loss, reduced respiration, and dehydration, are presumed to be the result of neglect and, therefore, frequently cited as deficiencies, rather than reviewed carefully to determine if they are a recognized part of the end-of-life process.55 The minimum data set measures are used in regulatory oversight and public reporting, thus encouraging more care at the end of life in that setting than may be needed or appropriate.56

Although more recent legislation such as the Affordable Care Act contains government incentives to create organizations that reward collaboration, coordination, and efficiency among providers, the government still evaluates and audits based on the size of claims submitted rather than the quality of care provided.57 Palliative care is a targeted area of investigation and audit.58

52 42 U.S.C. § 1814(a)(7) requires a prescriptive certification process, which discourages hospice use.
54 Haiden A. Huskamp et al., A New Medicare End-of-Life Benefit for Nursing Home Residents, 29 Health Aff. 130, 134 (2010).
55 Id.
56 Id.
58 Id. at I-12.
As Michael Specter recently commented on placebos and physicians’ decisions, “These are ethical judgments masquerading as science.”\(^{59}\) That could be said of many standards, statutes, and laws enacted in the name of protecting the health and welfare of the elderly subjectively enforced by federal and state agencies or their contractors. The clearest example may be the regulations adopted pursuant to court order in the case of *Estate of Smith v. Bowen*\(^ {60} \) and the provisions of the Omnibus Budget Reconciliation Act of 1987.\(^ {61} \) These are found at 42 C.F.R. Part 483 (frequently referred to as OBRA regulations). They contain compliance requirements that often produce unintended consequences relative to the quality of life for the elderly. As illustrated below, the regulations’ highly prescriptive nature, the subjective enforcement, the government surveyors’ lack of accountability, and the constant drumbeat from Congress and advocates to increase the literal enforcement of the regulations affect the physician/patient relationship.

Government surveyors indirectly affect the decision-making of physicians who favor palliative care by citing nursing facilities for not providing care that the patient’s physician may regard as futile. The classic example is the nursing facility cited for failing to provide cardiopulmonary resuscitation (CPR) on a person who was clearly dead because the nursing home resident did not have a do-not-resuscitate

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\(^{60}\) *Estate of Smith v. Bowen*, 656 F. Supp. 1093 (D. Colo. 1987) (analyzing compliance with and enforcing of the court order from *Estate of Smith v. Heckler*, 747 F.2d 583 (10th Cir. 1984) [hereinafter *Heckler*]). Plaintiffs initiated a class action in 1975 against the Secretary of Health and Human Services on behalf of Medicaid recipients residing in nursing homes in Colorado. *Heckler*, at 585. Plaintiffs alleged that the Secretary had a statutory duty under 42 U.S.C. §§ 1396-1396n (the Medicaid Act) to create a system to review nursing homes to ensure Medicaid recipients were receiving the optimal medical and psychological care they are entitled to under the Medicaid Act. *Id.* The plaintiffs further alleged that the system developed by the Secretary was “facility oriented” and not “patient oriented,” and thereby failed to meet the statutory mandate. *Id.* While distinguished in its holding by courts in other circuits, it remains a relevant example of this regulatory irony.

\(^{61}\) 42 U.S.C. § 1395 *et seq.*
The nursing home was further cited for not calling an ambulance and not sending the resident to the hospital.\(^{63}\)

Exacerbating this situation is the fact that although the surveyors may be sanitarians or dietitians not trained to make nursing decisions, they question physician decision-making and criticize professional opinions that advise a nursing facility to withhold futile care to further a more natural death.\(^{64}\) This discourages person-centered, collaborative decision-making by third-party qualified professionals (e.g., physicians, physical and occupational therapists, mental health professionals). Therefore, the nursing facility will act defensively to overtreat its residents, frequently resulting in the provision of futile care.

The OBRA regulations are supplemented by a State Operations Manual (SOM), which contains over 800 pages of guidance and direction to government surveyors on how to apply the OBRA regulations. The threshold requirement of the OBRA regulations is found in 42 C.F.R. Section 483.25 and provides as follows:

Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.

This goal is met by compliance with additional regulatory requirements. The SOM provides direction to the surveyors about how they are to apply those regulations and determine compliance. Significantly, nowhere in the over 800 pages of the SOM is there any explicit mention of death or the dying process.


\(^{63}\) Id.

\(^{64}\) 42 C.F.R. § 488.314(a)(2).
Physicians may be brought late into the process, although their earlier intervention could have provided patients information and choices affecting their end-of-life care. Frequently, this is because institutional healthcare providers like hospitals and nursing homes most frequently are required by law to discuss with patients the need to make end-of-life decisions such as living wills, durable powers for healthcare, or the designation of choices, such as DNR orders. How and if institutional healthcare providers choose to bring physicians into the process is not necessarily a function of governmental regulation. Once a patient makes an initial decision, there may be little incentive on the part of the institutional healthcare provider to revisit the issue.

Even after a decision is made by a patient on end-of-life care, whether that decision is honored depends on a number of factors, including the institutional healthcare provider’s policies, the provider staff’s degree of understanding of the institution’s policies, and standards of care set by third parties such as the American Heart Association. Clearly, statutes, regulations, and the SOM more frequently support the patient/resident’s extension of life unless the patient/resident’s intentions are clearly articulated in writing to the caregivers. Even then, the provider policy may require advice or approval by the patient’s physician to effectuate the patient/resident’s decision.

What begs the question is that often the discussion with the patient/resident about end-of-life issues occurs at both a time and in a setting when it is not likely that the patient/resident is able to make a fully informed decision. Neither physician reimbursement nor current stan-

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standards of care encourage physicians to engage in a discussion about end-of-life decisions early enough in the disease state process to allow time during a less stressful period for the patient/resident to confer with family members, clergy, and others to make an informed decision. Once the patient/resident reaches an institution, environmental factors may overtake the situation, and regulatory requirements more fully supporting extension of life are utmost in the minds of the caregivers who otherwise would be in a position to provide information about end-of-life decisions to the patient/resident. When an emergency occurs, the standards of care favor extension of life unless the patient/resident clearly has articulated his or her wishes not to be resuscitated.68

Laws and practice gradually are beginning to accommodate the patients’ wishes in more practical ways. The Physician Orders for Life-Sustaining Treatment (POLST) is a medical order form that accomplishes two purposes.69 It turns an individual’s treatment wishes into actionable medical orders, and it is portable as patients move from one care setting to another. It honors the patient’s end-of-life treatment preferences whether they are to limit treatment or to continue normal care. It does not replace the advance directive. Although the advance directive is needed to appoint a healthcare surrogate and provide instructions for future life-sustaining treatments, the POLST accompanies an advance directive as a physician order.

An example of non-governmental guidelines adopted by governmental agencies is the American Heart Association’s guideline on CPR. It states that CPR should be provided unless: (i) there is a DNR order; (ii) there are signs of irreversible death, such as rigor mortis, decapi-

68 Omni Manor Nursing Home v. Centers for Medicare & Medicaid Services, D.A.B. No. 1920 (2004), available at www.hhs.gov/dab/decisions/dab1920.htm. In this case, the designation to the nursing home by the resident for “DNR Comfort Care” was found insufficient because the form did not also contain a specific designation of a “Do-Not-Resuscitate Order.”
69 For more information about POLST, visit National POLST Paradigm at www.polst.org/.
Impediments to End-of-Life Discussions

tation, decomposition, or dependent lividity; or (iii) no physiological benefit can be expected because vital signs have deteriorated despite maximal therapy (for example, progressive septic or cardiogenic shock).

Thus, unless the person is “extremely dead,” the healthcare provider is expected to give CPR even in situations where care may be futile. Even where registered nurses can provide sufficient information to allow the physician offsite to declare a resident dead, federal regulations do not permit the facility to disregard the resident’s advance directive to administer CPR.

Emergency Medical Treatment and Active Labor Act

Even where there may have been proper and appropriate discussions of end-of-life care decisions, federal law can intervene to interrupt what would otherwise be a process of personal decision-making. This may be illustrated best in the Baby K case. In this case, an infant was born with multiple birth defects, no cognitive awareness, and an inability to see, hear, or interact with her environment. The child was having severe breathing difficulties and was treated in the hospital’s emergency department and placed on a mechanical ventilator. Thereafter, the baby was returned on numerous occasions to the hospital, which finally sought a declaratory judgment that it was not required to provide respiratory support or aggressive treatment under the Emergency Medical Treatment and Active Labor Act (EMTALA).

The Federal District Court denied the hospital’s request, and the hospital appealed to the United States Court of Appeals for the Fourth Circuit. That Court affirmed the District Court’s holding.

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70 Lakeridge Villa Healthcare Ctr., at 10.
71 Id. at 11.
72 In re Matter of Baby K, 16 F.3d 590 (4th Cir. 1994).
73 Id. at 592.
74 Id.
75 Id.
76 Id. at 593.
that EMTALA contains no exceptions to the requirement that physicians and hospitals must provide a medical screening examination to patients who present to the emergency room and stabilize those with emergency conditions. Therefore, the physicians were required to provide stabilizing treatment to Baby K. The Court recognized that the medical care was futile, but nonetheless held that the hospital had to continue to provide respiratory treatment to Baby K each time she presented to the hospital emergency department.

Although this may be an extreme case, it does illustrate how public policy in the form of legislation can be at cross-purposes with the physician’s ability to provide an explanation to patients and their families and obtain consensus on issues of end-of-life care. Frequently, it is difficult to obtain that consensus even within the nuclear family. In the Baby K case, it provided an opportunity for those dissenting family members to seek and obtain what would otherwise be futile treatment.

**Need for Culture Change**

Studies of patients with serious illnesses reveal that they desire to control pain and symptoms, avoid inappropriate prolongation of the dying process, achieve some control over their end of life, relieve the burdens on their family, and strengthen relationships with loved ones. However, data from some studies indicate that 50% of patients with life-threatening illnesses die within 6 months of entry into a hospital and had moderate to severe pain in the last 3 days of life, and 38% of those who died spent more than 10 days in an intensive care unit in a coma or on a ventilator.

Recent studies show that family caregivers would like to have their loved ones’ wishes honored; to be included in the decision-making processes; to receive some type of support or assistance at home, including practical help with transportation, medicines, and equipment; to have

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77 Id. at 597.
78 Lupu.
79 Id.
help with their loved ones’ activities of daily living such as bathing, feeding, and toileting; to get honest information; to have continual access to professional caregivers; to be listened to; to have their privacy respected; and to be remembered and contacted after the death of a loved one.\textsuperscript{80} Other studies show that family members do not believe they have sufficient contact with their physicians, emotional support, information about what to expect with the dying process, and help with pain.\textsuperscript{81}

Studies show that palliative care patients have a higher quality of life and lower depression rates at 12 weeks after diagnosis, use less aggressive care, use more hospice care, and live longer after diagnosis.\textsuperscript{82} Studies also show that palliative care clarifies goals of care with patients and families, helps families to select medical treatment and care settings to meet their goals, and assists with decisions to leave the hospital or to withhold or withdraw death-prolonging treatments that do not help to meet their goals.\textsuperscript{83}

As mentioned throughout this Comment, there are also cost savings. Of course, the cost for healthcare does not fall only on the government but also on employers. Studies have shown that the estimated lost productivity of working caregivers to be $17.1 billion to $33.6 billion per year in 2002/2003.\textsuperscript{84} The number of caregiving employees who left the workforce entirely in 2004 was 2.4\%.\textsuperscript{85} These numbers may not capture the entire cost to the employer. The cost of lost productivity when employees are distracted by healthcare decisions can add to the numbers.

\textsuperscript{80} Id.
\textsuperscript{81} Id.
\textsuperscript{82} Jennifer S. Temel et al., Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, 363 NEW ENG. J. MED. 733, 739–41 (2010).
\textsuperscript{83} Lupu.
\textsuperscript{84} J. Brent Pawlecki, End of Life: A Workplace Issue, 29 HEALTH AFF. 141 (2010).
\textsuperscript{85} Id.
For employers offering health benefits, the direct cost is substantial, with 25% of expenses paid during the last year of a person’s life.\textsuperscript{86} If employers would support the development of programs to encourage conversations about end-of-life issues, the completion of advance directives, and help in identifying healthcare proxies, it could result in substantial cost savings while allowing the private sector to effect a culture change without direct government involvement. A private sector culture change may pave the way to change government policy, by allowing the dying process to be viewed in a politically neutral way, and thus discourage further politicizing the issue. At the same time, employers must examine their employees’ benefit plans to determine if coverage and payment policies discourage physician conversations about end-of-life issues.

There are other public policy implications. For example, studies have shown that a person’s race has a substantial impact on the level of care at the end of life. African Americans were almost twice as likely as Caucasians and others to choose full code status and half as likely to choose withdrawal of life support.\textsuperscript{87} Other studies have shown that black patients tend to receive less information from physicians than white patients, and family members of black patients who have died describe more communication problems at the end of life than families of white decedents.\textsuperscript{88} The same study showed that hospice care is underused among black patients at the end of life.\textsuperscript{89} It is yet to be determined whether this is because this population cohort has less access to physicians or because the physicians to whom they have access are reluctant for cultural or other reasons to discuss end-of-life issues.

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\item \textsuperscript{86} Id.
\item \textsuperscript{87} Rebecca W. Johnson et al., \textit{Differences in Level of Care at the End of Life According to Race}, 19 AM. J. CRITICAL CARE 335, 337 (2010).
\item \textsuperscript{88} Jennifer W. Mack et al., \textit{Racial Disparities in the Outcomes of Communication on Medical Care Received Near Death}, 170 ARCHIVES INTERNAL MED. 1533, 1534 (2010).
\item \textsuperscript{89} Id. at 1538.
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Studies of the effects of palliative or hospice care on Medicaid expenditures also show cost savings. For example, patients provided with palliative care who died in the hospital had lower intensive care costs. There is an approximately 40% decrease in intensive care costs for palliative care patients discharged alive from the hospital. These cost savings can be significant because studies show that approximately 60% of all Medicaid expenditures are spent on acute hospital services and that the sickest 5% of patients with Medicaid coverage, largely the elderly and disabled, account for 57% of total program spending. The dually eligible nursing home population represents 7% of the Medicaid population but accounts for 52% of Medicaid spending. Therefore, these cost savings from palliative care and hospice should be considerable among this population as well.

Needed changes in the hospice care Medicare requirements include providing necessary direct care treatment of the terminal condition to repair damage caused by the disease state as well as to reduce morbidity when appropriate. It also should include recognition that the six-month benefit cap is unrealistic, impractical, and prevents more frequent use of palliative care like hospice because of physicians’ fear of investigation for false certifications. As discussed above, the current six-month terminal prognosis is a barrier for persons with non-cancer, chronic terminal illnesses, as well as for those with cancers lacking a typical course, because it is difficult to predict the death of these patients. Fortunately, not every cancer patient suffers from pancreatic cancer that routinely runs its course in six months or less.

The six-month certification requirement affects persons dying in skilled nursing facilities and other settings. Seventy-two percent of

90 R. Sean Morrison et al., Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries, 30 Health Aff. 454, 461 (2011).
91 Id. at 457.
92 Id. at 458.
93 Id. at 459.
94 Id. at 460.
95 Id.
96 See supra note 41 and accompanying text.
persons with non-dementia chronic terminal illnesses, however, do not die in skilled nursing facility settings. But for those who do as well as those who do not, the requirement that persons entering hospice must forego other Medicare Part A care when such care is related to the terminal illness needlessly prevents those patients from enjoying a better quality of life during the dying process. The result is that hospital care and curative treatments are abandoned, when, as stated above, they could help to alleviate morbidity during the spell of illness. The elimination of this prohibition would better account for the needed change in the intensity of hospice services toward the end of life.

Studies have shown that a more collaborative approach to palliative care is a cost saver as well. The prospective payment system for acute care institutions reimbursing based on diagnosis-related groups (DRGs), as well as the reimbursement system for physician services, discourage care coordination. The result not infrequently is unnecessary care at the end of life. Perhaps society is ready to put into practice the good death concept introduced in the Institute of Medicine report from the late 1990s. A good death is one that is “free from avoidable distress and suffering for patients, families, and caregivers in accordance with patients’ and families’ wishes and consistent with clinical, cultural, and ethical standards.” On the other hand, a bad death is one that “includes needless suffering, disregard for patient or family wishes or values, and a sense among participants that norms of decency have been offended.”

Government policies in the form of survey standards applicable to institutional providers encourage futile care by frequently eliminating the choice of their patients/residents who prefer good death to bad

97 R. Sean Morrison et al., Cost Savings Associated with US Hospital Palliative Care Consultation Programs, 168 ARCHIVES INTERNAL MED. 1783, 1783 (2008).
99 Id.
100 Id.
Hospital quality measures and reporting requirements focused primarily on process measures associated with life extension (e.g., Department of Health and Human Services’ Hospital Compare) thus create a disincentive for appropriate treatment of patients where death is an expected or preferred outcome. Physicians react as expected to these requirements by avoiding end-of-life discussions with patients.

The Patient Protection and Affordable Care Act

When Sections 138 and 1233 of H.R. 3200, the earlier version of the Affordable Care Act (ACA), were proposed, the legislation already was regarded as controversial for many reasons. Its highly prescriptive nature and the circumstances of its enactment created suspicion among many Americans that the government’s real objective as the largest single third-party payor was to save money rather than improve health-care. Therefore, when the phrase death panels was used to describe the mechanisms and requirements contained in these two proposed sections, it reinforced many Americans’ fears about the overall legislation. Whether this was a failure by the then-leadership in Congress or the political exploitation of a situation by opponents of the administration, the provisions were not enacted. Perhaps this defeat echoed the choice made in 1990 in the PSDA to require only documentation and not conversation about advance directives and end-of-life care.

The provisions of the ACA are being implemented through pilot projects and other initiatives to provide an opportunity to create a cultural change by encouraging providers to achieve certain economic goals. One is the Bundling Pilot Project, whereby the government will test whether placing payments within a single provider who then pays for services and items needed for an episode of care will create shared

101 Robert G. Holloway & Timothy E. Quill, Mortality as a Measure of Quality: Implications for Palliative and End-of-Life Care, 298 J. AM. MED. ASS’N 802 (2007).
103 Id.
Another is the concept of the accountable care organization (ACO).\textsuperscript{105} The ACO is intended to encourage greater collaboration and cooperation among providers to create more efficient delivery of healthcare and thus achieve cost savings which can be shared among them. The Centers for Medicare & Medicaid Services (CMS) has issued regulations under ACA, Section 3022.\textsuperscript{106} This section establishes the Medicare Shared Savings Program under which ACOs may operate. The Shared Savings Program is designed to create a new framework for hospitals, physicians, and other healthcare providers to work together to improve quality and reduce the cost of healthcare services covered by Medicare. The regulations define an ACO as a legal entity recognized under state law that consists of Medicare-enrolled providers or suppliers that work together to manage and coordinate care for Medicare fee-for-service beneficiaries.\textsuperscript{107}

This concept could achieve cost savings by adding palliative care and hospice to the mix of alternative services for patients. Cost savings can also be achieved from the medical home—the concept in the ACA to provide comprehensive care that facilitates partnerships between individual patients and their personal providers and, when appropriate, the patient’s family.\textsuperscript{108} Because payment to physicians coordinating care in the medical home is on a per-member per-month basis, the cost savings that can be achieved from palliative care and hospice could be significant. Other demonstration projects such as the Independence and Home demonstration project could benefit from palliative care and hospice. This concept will test which of the following provisions will achieve cost savings: the provision of physician or nurse practitioner–directed home-based primary care and care coordination across all treatment settings for beneficiaries with two or

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\textsuperscript{104} Patient Protection and Affordable Care Act, § 3023, 42 U.S.C. § 1395cc-4.  \\
\textsuperscript{105} Id. § 1395jjj.  \\
\textsuperscript{107} Id. § 425.20.  \\
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more chronic conditions, a non-elective hospital admission in the last year, prior rehabilitation, or two or more functional dependencies. Under the ACA there will be quality reporting requirements for hospices beginning in 2014. It is presumed that accrediting standards will be developed to meet that requirement.

As the debate continues between those who favor single payor universal coverage and those who wish to maintain a system that engenders personal responsibility in individuals seeking care, consideration must be given to the structure of existing healthcare delivery systems to determine whether they are shaping the choices of the patients and their families and encouraging, rather than discouraging, physician involvement in the decision-making process.

**Conclusion**

For physicians to engage in meaningful discussions of end-of-life care, a more thoughtful commitment is required from all branches of government as well as standard-setting organizations, not only to support removing impediments to those conversations but to reappraise existing law and standards to create a marketplace in which providers, patients, payors, and policymakers can agree to support these discussions. A growing body of professional literature speaks to each aspect of the problem. As long as the government and perhaps third-party payors are viewed as suspect in their role to support these discussions, it will be difficult to achieve the change in both culture and society necessary for physicians to feel comfortable initiating the subject. Perhaps, at some point, provisions such as Section 1233 of the original Health Care Reform legislation can be considered in a political atmosphere that is less charged and more polite. Until then, physicians and other healthcare providers may continue to feel challenged in exercising the responsibility to initiate these discussions in the face of the current impediments.

109 Id. § 3024, 42 U.S.C. § 1395cc-5.
110 Id. § 3004(c), 42 U.S.C. § 1395f(i).