Dying Discourse: Contextualizing Advance Care Planning

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I. INTRODUCTION ............................................................................ 237
II. CHANGING PERSPECTIVES ON DEATH AND DYING ................. 239
   A. Approaches to Death and Dying in an Historic Context........... 240
   B. Transitional Attitudes Toward Death .................................... 242
   C. Contemporary Attitudes Toward Death and Dying in the United States ............................................................. 244
      1. The Old and the New, Compared ........................................ 244
      2. New Attitudes Toward Life, New Attitudes Toward Death ................................................................. 246
III. DEATH AND DYING: DEMOGRAPHIC CHANGE, SOCIAL CHANGE, AND MEDICAL INNOVATIONS ....................................................... 247
      A. Shifting Patterns of Death and Dying ................................ 247
      B. Medical Developments ......................................................... 248
IV. SOCIAL AND LEGAL RESPONSES TO DEATH AND DYING .......... 251
      A. Informed Consent and Patient Autonomy ............................ 251

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B. Respecting Patient “Autonomy”: Patients Without Capacity ............................................. 253
1. Quinlan and its Context ....................................................... 254
   a. Karen Quinlan’s Story ................................................... 255
   b. Quinlan in New Jersey’s Highest Court .................. 257
   c. Confusion About the Meaning of Death: “Brain Death” ................................................... 259
2. Cruzan ............................................................................. 260
3. Schiavo ........................................................................... 262
4. The Lessons of Quinlan, Cruzan, and Schiavo .............. 264
C. Legislative Responses .......................................................... 266
D. Physician-assisted Suicide and Euthanasia: A “Slippery Slope” or a Different Matter? ........... 269

V. PAYMENT FOR ADVANCE CARE PLANNING: A NATIONAL DEBATE ................................................. 271
A. Advance Care Planning and Fabricated Claims: Serving Partisan Political Ends ....................... 272
   1. Social Media: Defeating the Coverage Provision .... 273
   2. Death Panels and the Abortion Debate .................... 276
   3. The Irony of the “Death Panel” Claim and the Implications of its Success ......................... 278
B. Revivifying the Coverage Provision ..................................... 279
   1. Proposals that Failed to Receive Adequate Support ..... 279
   2. 2015: A New CMS Proposal and a Finalized Rule ..... 281

VI. ADVANCE CARE PLANNING: EDUCATION AND IMPLEMENTATION .................................................... 283
A. Encouraging Conversations About Advance Care Planning ...................................................... 284
B. The CHAT Project .................................................................. 286
   1. The Law and Advance Care Planning ......................... 288
   2. Clinicians and Advance Care Planning .................... 292
   3. The Community, Advance Care Planning, and Public Health ................................................... 294
C. Implications for the Cost of Good Health Care? ................................................................. 294

VII. CONCLUSION ............................................................................. 296
Ah, Lord, teach us to consider that we must die, so that we might become wise.¹

I. INTRODUCTION

During the last four decades, the law has erected a framework that facilitates medical decision making for terribly ill persons who lack the capacity to make decisions on their own. As a practical matter, attorneys in every state can now guide clients through the process of advance care planning. The details vary from state to state, but uniformly throughout the states people can identify surrogate decision makers and delineate preferences for surrogates to follow should the principal need medical care while the principal lacks decision-making capacity. Still, this body of law has been only partially successful in easing the process of dying for patients, the burden on family members, and the choices facing clinicians.

Alongside the law’s responses, clinicians²—and the health care facilities within which they work—increasingly consider how best to respond to the needs of dying or terribly ill patients who lack capacity. Attitudes among clinicians toward end-of-life care have transformed dramatically in the last four decades. When New Jersey’s highest court entertained the case of Karen Ann Quinlan in the mid-1970s,³ the court reported that Karen’s clinicians, as well as experts who testified, agreed that withdrawing respiratory support “would not conform to medical practices, standards and traditions.”⁴ Now, most clinicians endorse withholding and withdrawing care from terminally ill patients as an accepted part of end-of-life care (assuming that the patient voices or once voiced that preference).⁵ Many hospitals now offer educational programs that

¹ Johann Sebastian Bach, Bach Cantata BWV 106 (“Gottes Zeit Ist die Allerbeste Zeit”). The language is a liberal translation of Psalm 90:12.
² This Article uses the term clinicians to refer to health care professionals, especially to physicians, nurses, and physician assistants.
⁴ Quinlan, 355 A.2d at 655. At the time, Karen was in a persistent vegetative state. Her treating neurologist refused to be part of any order to remove Karen’s respirator. In re Quinlan, 348 A.2d 801, 819 (N.J. Super. Ct. Ch. Div. 1975). Even at the time some clinicians differentiated cases such as Karen’s involving a persistent vegetative patient from cases involving terminally ill patients. See DAVID ORENTLICHER ET AL., BIOETHICS AND PUBLIC HEALTH LAW 271 (2d ed. 2008); see also infra Part IV.B.1.a (summarizing Quinlan).
guide clinicians through the difficult task of assisting patients and their loved ones in dealing with medical choices faced by people who are very ill or dying.\(^6\)

Changes in the approaches of law and medicine to appropriate care for terminally ill patients developed within a larger socio-cultural frame. Within that frame, autonomous individuality has largely trumped the primacy of communal hierarchy within the world of health care. The informed consent doctrine constitutes a central outgrowth of that shift.\(^7\)

More generally, new understandings of personhood and community, spawned by the Enlightenment and the Industrial Revolution, facilitated changes in society’s understanding of death and dying. This Article considers the development of advance-care-planning laws within the context of shifting visions of death and dying in the Western world.

Curiously, the most dramatic shift in visions of death and dying—one that has privileged dying over death as the focus of public attention—seems to have appeared as much as a century before the development of medical technology that actually facilitated the prolongation of dying long beyond that which was previously possible. Society’s focus on dying—a part of living, however particular—it may serve to displace anxiety about death and even to mask the inevitability of death—a matter largely entertained through the lens of religious belief before the nineteenth century. The focus on dying’s demands has produced a series of responses from law, medicine, and society. These responses, in turn, reflect attitudes about illness, health care, the clinician-patient relationship, and personhood.

Part II of this Article contextualizes consideration of advance care planning within the broad sweep of Western history’s shifting visions of death, and then later of dying. Then, Part III offers basic demographic facts about the reality of death and dying in the contemporary United States. Further, it describes developments in medicine that facilitated a number of demographic changes, beginning in the second half of the twentieth century. In the last three or four decades of the twentieth century, the law began to respond to the new reality of dying. Part IV details the judicial and legislative responses to medical decision making for pa-

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\(^6\) For the most part, advance care planning is assumed to pertain to end-of-life decision making. In addition to that, however, advance care planning can be important for very ill patients without capacity who are not facing terminal conditions.

\(^7\) See infra Part IV.A.
tients without capacity that culminated in every state’s providing for advance care planning by the end of the twentieth century.

Despite the ubiquity of advance care planning laws, most people still fail to complete advance directives, and even those who do complete these legal forms do not necessarily talk with their prospective surrogate decision makers or with their clinicians about their preferences and needs. Part V reviews a crucial development—long awaited and only partially in place at this time—that will effectively define advance care planning as a component of good health care. An important component of that development, discussed in Part VI, involves paying clinicians to engage in advance-care-planning conversations with patients. In July 2015, Medicare proposed two billing codes that will pay clinicians to engage in such conversations. The codes are limited, but offer promise that other insurers will follow this lead and that the Medicare codes will be broadened over time. Finally, the last Part of this Article considers an interdisciplinary model for educating the public and professionals about the significance of advance care planning. Only through open conversations about medical preferences and end-of-life choices among patients (or potential patients), surrogate decision makers, and clinicians can those in the latter two groups gain the knowledge needed to wisely translate a patient’s wishes into actual decisions in concrete situations that often differ from those referenced on the face of advance directives. This, simply put, is part of and a model for good health care.

II. CHANGING PERSPECTIVES ON DEATH AND DYING

Societies throughout time and space have responded in various ways to death. Only recently has dying (as contrasted with death) received significant attention. Until the twentieth century, few people experienced long periods of dying, and no one died connected to life-support machines. Throughout human history, death has occasioned a panoply of emotions and has variously been feared, celebrated, be-moaned, or welcomed.

In much of the world today, death has been medicalized and legalized. These processes have not developed ex nihilo. They reflect broader trends and respond to deeply embedded assumptions about personhood.

8 See infra Part V.
9 See infra notes 274–282 and accompanying text.
10 Those assumptions contrast with assumptions of other cultures and of Western culture
A central feature of death in the modern world is the frequency with which it is preceded by a sustained period of illness, often chronic illness. Further, in contrast with responses to death during almost all of the last millennium in the West, death, although understood as inevitable, is often unexpected when it arrives. The long process of dying that precedes many contemporary deaths, has not conditioned society to accept death. Rather it has conditioned people to presume (despite the ubiquity of death) that death can always be held at bay a while longer. This not only differentiates contemporary understandings and experiences of dying and death from those of earlier times and other places, but it contains clues that explain contemporary approaches—both medical and popular—to end-of-life medical decision making and to the laws that channel those approaches.

This part offers a very brief summary of shifting attitudes toward death and dying over time. Section A reviews predominant attitudes toward death from the medieval period to modern times. Then, Section B examines shifting attitudes toward death and dying in the nineteenth century. Finally, Section C of this Part considers assumptions in the U.S. today about death and about how people die and how they should die. Contemporary attitudes about death and about the process of dying undergird the law’s developing rules about medical decision making for people without capacity, as well as medicine’s responses to dying patients.

A. Approaches to Death and Dying in an Historic Context

In The Hour of Death, a remarkable history of attitudes toward death, Philippe Aries calls attention to an “ancient attitude toward death”—dominant during the early Middle Ages—extending back to ancient history and perhaps, even to prehistory. During this long period of time, explains Aries, the “common ordinary death” (conceived as a “good” death) was preceded, shortly before death approached, by a warning to the person about to die. That person would then acknowledge that death’s warning had been issued and would communi-

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13 Id. at 6.
cated that fact to those surrounding the sick-bed. In this approach to the good death, only the dying person knew how much time was left to him or her: “Neither [the dying man’s] doctor nor his friends nor the priests . . . know as much about it as he.”

Deaths that did not warn were viewed as “the absurd instrument of chance.” Such deaths—known as *mors repentina* (sudden death)—were liable to bring shame and ignominy. Indeed, a *mors repentina* was likely to have been met with silence rather than with the elaborate rituals that generally surrounded a death that properly warned a dying person of its imminent arrival. Here Aries remarks quite stunningly: “Anyone who is aware of the ostentatious displays of mourning that characterized this period can judge the significance of this silence, which seems modern.” That is, the comparative silence that so generally accompanies death in the contemporary world accompanied only a death deemed ignominious in earlier ages. Even more remarkable, Aries explains that in the modern world, the “sudden” death—for instance, death in an automobile accident or by way of a gunshot wound—is viewed as extraordinary. Modern responses to unexpected, sudden deaths tend to be more outspoken and public than responses to other deaths.

Aries found references to a good death as a death that warned before it separated a dying person from life in the literature of the Middle Ages, including the Song of Roland, the poems of Tristan, and tales of the Round Table. Sometimes, death’s warning came in the form of apparitions or dreams. Sometimes, as in the case of Roland, death announced itself as a feeling that death had begun to “invad[e] [the]

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14 Aries illustrates this approach to the good death through reference to Chanson de Roland, the poems of Tristan, and stories of the Knights of the Round Table. *Id.* at 5–6.

15 *Id.* at 6. With exceptions, Aries relies on male pronouns. It is hard to know whether that reflects a different experience for dying women or simply that Aries did not know about, or chose not to focus on, women’s death experiences. Were it the case that females experienced death differently than males and were that difference generally known, Aries would likely have described the difference. He does, however, consider images depicting the death of the Virgin. ARIES, *supra* note 12, at 141, 250, 311.

16 *Id.* at 6.

17 *Id.* at 10.

18 *Id.* at 10.

19 See ARIES, *supra* note 12, at 11.

20 *Id.* at 11 (emphasis added).

21 See *id.* at 6.

22 *Id.* at 11. Such deaths in the modern world—deaths in car accidents or plane crashes or deaths due to violence—generally receive more publicity than other deaths.


24 *Id.* at 6–7.
Aries suggests that changes in attitudes toward death are glacial.\textsuperscript{26} Even as late as the eighteenth century, it was considered impressive to have fore-knowledge about the timing of one’s death.\textsuperscript{27} By this period, new attitudes toward death were becoming evident, existing for some time alongside the old attitudes. The new attitudes flourished in the context of broad changes in society, law, and medicine. All of these changes evolved rapidly in the twentieth century.\textsuperscript{28}

\section*{B. Transitional Attitudes Toward Death}

Tolstoy’s 1886 novella, \textit{The Death of Ivan Ilyich}, narrates the story of one man’s death.\textsuperscript{29} The novella reflects an attitude toward death that echoed that which had been—as well as that which would soon become—far more common. By this time, there were significant changes in the personnel surrounding death. In place of, or at least alongside the role once occupied by the priest, Aries points to that of the doctor.\textsuperscript{30} By the end of the nineteenth century, the process of medicalizing death had begun.\textsuperscript{31}

Ironically, with the medicalization of death, came a fierce effort to mask, and indeed to deny, death. With the prophetic vision of the great novelist, Tolstoy, who wrote the story of Ivan Ilyich’s death at the end of the nineteenth century, remarked on both the disguise of death and on its medicalization.\textsuperscript{32} The constancy of the pretense that surrounded the death of Ivan Ilyich—that he was not dying when he clearly was—succeeded in “degrad[ing] the formidable and solemn act of Ilyich’s death.”\textsuperscript{33} Today, the tenacity of that lie and its frightful power to disguise the truth is abating, but it has not disappeared from contemporary responses to dying. Tolstoy mined that lie. The narrative of the novella

\begin{footnotesize}
\begin{enumerate}
\item \textit{id.}
\item \textit{id.} at xvi (“Changes in man’s attitude toward death either take place very slowly or else occur between long periods of immobility. Contemporaries do not notice these changes because these periods of immobility span several generations and thus exceed the capacity of the collective memory.”).
\item See \textit{ARIES, supra} note 12, at 9.
\item See \textit{infra} Part III.
\item \textit{ARIES, supra} note 12, at 564.
\item \textit{id.} at 563.
\item \textit{id.} at 567.
\item \textit{id.} (quoting \textit{TOLSTOY, supra} note 29, at 142-43).
\end{enumerate}
\end{footnotesize}
focused not on Ilyich's death, but on Ilyich's living, indeed Ilyich's coming to life for the first time, as he combatted the lies imposed on the process of his dying.

Almost a century after Tolstoy wrote *The Death of Ivan Ilyich*, a French priest, Father Francois de Dainville, spoke with another priest about a salient consequence of Dainville's own medicalized dying: "They are cheating me out of my own death."34 Father Dainville died in the early 1970s in a hospital's intensive-care unit, invaded by a myriad of tubes aimed at sustaining life.35 The lie that characterized Ilyich's fictional dying can be equated with the lie about which Father Dainville complained. The lies were of a similar sort. But the lie that compromised Dainville's dying was imposed in a new manner; it was a lie grounded in the life-sustaining tubes that characterized Dainville's dying and death. The medicalization of dying—a process now defined by life-sustaining technology36—wrapped the end-point in a new variant of the lie that had aimed to mask Ivan Ilyich's fictional death a century earlier.

The two variants—the effort to mask death (the lie, as it were) along with the prolongation of dying through the use of life-sustaining treatments merged in the twentieth century with the routine hospitalization of dying people. In 1900, most people in the United States died at home; however, by the start of the twentieth century, most died in hospitals.37 The hospital death facilitated society's interest in hiding death from the public gaze. And by the middle of the twentieth century, increasingly effective forms of life-sustaining care within hospitals encouraged the myth that death, much like disease, could be conquered by science and technology.

Thus, in the worlds inhabited by Roland, Tristan, and the Knights of the Round Table, a dying person was expected to intuit his own death and to announce death's arrival.38 That attitude toward death survived into the eighteenth century.39 But soon, alternative attitudes toward death were competing with those that defined death during the previous millennium.

34 ARIES, supra note 12, at 567.
35 Id. at 572.
36 See infra Part III.B.
38 See supra notes 13–19 and accompanying text.
39 See supra notes 29–31 and accompanying text.
Soon, the medicalization of death—which began even before the development of sophisticated life-sustaining technology—rendered dying as significant as death for most people. By the twentieth century, these new attitudes toward death and the increased significance paid to the period of dying harmonized with the move toward a society in which large segments of the population found themselves (or chose to be) largely bereft of religious and other traditional anchors. Further, the traditional approach to death as described by Aries was transformed by new understandings of personhood, focused on autonomous individuality rather than on community and connection.30

C. Contemporary Attitudes Toward Death and Dying in the United States

Yet, curiously some aspects of the methods through which contemporary Americans are urged to prepare for dying and death (for instance, through attention to advance care planning in the late twentieth and early twenty-first centuries) might seem to be a modern equivalent of the hope or expectation of the ancient and medieval worlds that death warn dying people of its approach.41 The differences are fundamental, of course, but still some similarities can be noted, even as contemporary law and medicine have responded with a distinctly modern idiom.

1. The Old and the New, Compared

The “good death” of previous centuries—one that relied on dreams and visions to warn a person about to die as death arrived42—is neither common nor deemed better than other deaths by the contemporary world. That antiquated vision of death was grounded on assumptions about the after-world and religious powers that survive only in pockets

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30 In the second half of the twentieth century, society broadly displaced “traditional” values that defined family relationships and doctor-patient relationships in terms that valued hierarchy and community with values that focused on relationships through the lens of autonomous individuality. See, e.g., Lindsay F. Wiley, Health Law as Social Justice, 24 CORNELL J.L. & PUB. POL'Y 47, 105 (2014) (noting significance of individualism to world of health care as a focus that impoverishes the notion of community and displaces it with a notion of autonomous relationships); see also Janet L. Dolgin, Biological Evaluations: Blood, Genes, and Family, 41 AKRON L. REV. 347, 354–66 (2008) (considering these cultural shifts in context of twentieth century family).

41 See supra Part II.A.

42 See supra notes 23–24 and accompanying text.
of the largely secular, contemporary United States. The preface to the Institute of Medicine’s 2014 report on dying in America notes that “[f]ew people really have the opportunity to know when their death will occur.”

At least one important function lurking in an earlier age’s commitment to a notion of the “good death” has parallels in the modern world. These parallels attempt—as did the notion of a good death in Europe in earlier centuries—to make sense of death, to presume an order of a blessed sort when faced with the potential chaos death might suggest. Although death no longer warns as impressively as it once did, physicians and nurses may be aware that a patient will soon die. There is still reluctance among physicians to advise patients that death will likely soon arrive, even when physicians are aware of that reality. Increasingly, however, they are being encouraged to be forthright with dying patients or patients’ loved ones in the event that the patient is not able to communicate or understand medical information.

Elisabeth Kubler-Ross documents another instance of modernity’s awareness of death’s proximity with her delineation of the stages of responding to death’s approach.

Even more than these examples, advance care planning offers a plan for the good death in the twenty-first century. That death, as defined by Ellen Goodman, a founder of the Conversation Project, contrasts with a “hard death.” The good death is one in which the patient’s wishes were expressed and respected. Whether they’d had a conversation about how they wanted to live toward the end.

Both the notion of the good death of the medieval world and the planned-for death (or rather, dying) of the contemporary world presume the preservation of a social

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43 Philippe Aries reports on sociological studies that showed that members of contemporary Christian society have continued to have faith in God more often and more fully than they have continued to believe in an afterlife. ARIES, supra note 12, at 573. Aries further reports, however, that belief in an afterlife is more common among dying people than among others in the population. Id.

44 INST. OF MED. OF THE NAT’L ACADS., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE, at xi (2014) [hereinafter DYING IN AMERICA].

45 Id. at 159.

46 ARIES, supra note 12, at 589–90.

47 See ELISABETH KUBLER-ROSS, ON DEATH AND DYING 31–91 (Routledge ed. 2009) (1969) (noting that the stages of responding to death are denial and isolation, anger, bargaining, depression, and acceptance).

48 See infra Part VI.A.

order and some control over it, death notwithstanding.

2. New Attitudes Toward Life, New Attitudes Toward Death

Modernity's understandings of a good death have been shaped in response to challenges created by life-sustaining medical technology, developed in the middle years of the twentieth century. That development furthered the medicalization of dying, which began in the late nineteenth century, long before the appearance of life-sustaining technology. By the second half of the twentieth century, the process of dying in hospitals offered discomforting images to patients' families and friends, as well as even to patients' health care providers. Yet, too often those images were not acknowledged by health care professionals, leaving family members confused and helpless.

By the second half of the twentieth century, American medicine, which had made stunning strides in treating illness,\(^{50}\) seemed increasingly anxious to "treat" dying with the "miracles" of modern medicine—"miracles" such as antibiotics, dialysis, vaccines, and new surgical possibilities\(^{51}\)—as if it were but another serious illness. Even as virtually everyone knew that death had not been, and could not be, conquered, it began to seem as if dying could—and sometimes should—be prolonged for years and even decades.\(^{52}\) That vision harmonized with a vision of a new medicine that could advance without limits. But soon, medical professionals as well as the loved ones of dying patients began to question the wisdom of unrelieved aggressive care for dying patients, especially for those dying in pain.\(^{53}\)


\(^{51}\) See End of Life in America, ENDLINK: RESOURCE FOR END OF LIFE CARE EDUCATION, ROBERT H. LURIE COMPREHENSIVE CANCER CTR., NW. U., http://endoflife.northwestern.edu/introduction/what.cfm (last visited Jan. 20, 2016); see also Knoll, supra note 50, at 350.

\(^{52}\) See End of Life in America, supra note 51.

\(^{53}\) See, e.g., Ken Murray, How Doctors Die: It's Not Like the Rest of Us, But it Should Be, ZOCALO PUB. SQUARE: NEXUS, (Nov. 30, 2011), http://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus/; see also infra Part IV.D.
III. DEATH AND DYING: DEMOGRAPHIC CHANGE, SOCIAL CHANGE, AND MEDICAL INNOVATIONS

Before reviewing broad changes in the law that encouraged people to engage in advance care planning by the end of the twentieth century, this Part examines shifts in the demographics of dying and death that accompanied changes in social understandings of those matters. The most significant changes in this regard include increases in the average lifespan, with death often preceded by long periods of chronic illness, and, correlatively, the extension of the process of dying. This Part reviews those changes and notes several medical developments that facilitated the demographic changes.

A. Shifting Patterns of Dying and Death

The average lifespan in the United States increased from 47 years in 1900 to 75 years in 2000.\textsuperscript{54} Death during childhood was far more common in the early decades of the twentieth century than it was in the last part of the century.\textsuperscript{55} Before World War II, many people who survived childhood lived into their sixties, but far fewer of them than is the case today lived into their eighties and nineties.\textsuperscript{56}

As the average lifespan expanded, society increasingly assumed that death, though inevitable, would occur only years in the future. Even clinicians were beset with concern that they failed their profession and their patients if they could not “save their patients from death.”\textsuperscript{57} Many physicians, reflecting on, and perhaps also furthering, society’s shifting presumptions about death, accepted “the control of death as [their] mission in life.”\textsuperscript{58} Even today, over a quarter of adults in the United States have given almost no thought to their own deaths.\textsuperscript{59} And a large percentage of the population has not completed advance care planning documents.\textsuperscript{60} A 2013 survey of adults forty years of age or older found that less than half of that population had signed advance-directive forms.\textsuperscript{61}

This is the case even though images of a hospital death are both

\textsuperscript{54} See Lupu, supra note 37.
\textsuperscript{55} See End of Life in America, supra note 51.
\textsuperscript{56} See id.
\textsuperscript{57} Id.
\textsuperscript{58} ARIES, supra note 12, at 586 (writing about the second half of the twentieth century).
\textsuperscript{59} DYING IN AMERICA, supra note 44, at 3.
\textsuperscript{60} Id. at 11.
\textsuperscript{61} Id. at 127 tbl.3-1.
familiar and discomforting to most people, especially those who have visited dying friends or family members not enrolled in hospice or palliative care. More than three decades ago, Philippe Aries remarked that people in the modern world do not generally imagine the manner of their own deaths.\(^\text{62}\) They are, however, privy to hospital scenes of death that involve friends and loved ones “dying in a tangle of tubes all over [the] body, breathing artificially.”\(^\text{63}\)

Palliative care and hospice care offer options to very sick patients not comfortable with aggressive care. Yet, even as clinicians and the public seem ready to forego CPR and assistance with nutrition at the end of life, the nation has not witnessed a widespread pattern of less aggressive care for terminal patients. In the first decade of the twenty-first century, although a higher percent of people aged 65 and older died at home than in the previous decade and a half,\(^\text{64}\) utilization of intensive care units by patients at or near the end of life increased.\(^\text{65}\)

### B. Medical Developments

The average lifespan in the U.S. increased in the twentieth century as a result of various new medications, as well as improved sanitation, and other public health efforts.\(^\text{66}\) In particular, the availability of antibiotics by the 1940s gave medicine a powerful tool for controlling infectious diseases.\(^\text{67}\) Diseases such as pneumonia to which elderly people had often succumbed, comparatively free of distress, became treatable conditions. As a result patients with a slew of life-threatening conditions lived to linger, connected to life-sustaining technology.

The modern intensive care unit (“ICU”) emerged in the 1960s.\(^\text{68}\) Its creation was more or less coincident with the development of new

\(^{62}\) AR\-\(\text{E}IS\), supra note 12, at 593.

\(^{63}\) Id.


\(^{65}\) See id. at 473 tbl.2.

\(^{66}\) END OF LIFE IN AMERICA, supra note 51.

\(^{67}\) See id.

modes of providing ventilator support for patients with diminished respiratory function.69 This development, along with that of percutaneous gastrostomy ("PEG") tubes for feeding patients unable to swallow, revolutionized life-sustaining care for terribly sick and dying patients.70

By the 1930s, so called iron lungs—essentially tanks that surrounded patients’ upper bodies—provided respiratory support to some patients, but these machines could not compensate for complete respiratory failure, and they were most effective for patients who were conscious.71 By the 1960s, positive-pressure ventilation replaced the iron lung in newly fashioned ICUs.72 Throughout the last decades of the twentieth century and into the twenty-first century, technological developments offered patients improved modes of respiratory support.73

Development of feeding tubes (enteral feeding) that could easily be inserted into a patient’s body further facilitated sustaining life for very ill and dying people. Enteral feeding provides nutrition to patients without the ability to swallow or swallow easily.74 PEG tubes,75 developed by two Cleveland physicians in 1979, offered a viable alternative to feeding tubes that required surgery, accompanied by anesthesia.76 The two physicians who developed PEG tubes intended them to be used for pediatric patients who had difficulty swallowing.77 They specifically aimed to create a feeding tube that would eliminate the risks of surgery and anesthesia for young children and babies.78 About 25 years after the first use

69 Id. at 2.
70 See Sylvia Kuo et al., Natural History of Feeding Tube Use in Nursing Home Residents with Advanced Dementia, 10 J. AM. MED. DIRECTORS ASS’N 264 (May 2009), http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2733212/.
71 See Marini, supra note 68, at 1.
72 Id.
73 Id. at 3. Ventilators currently cost about $40,000, but low-cost ventilators are being developed. These promise to be especially useful in planning for and responding to pandemics. See Kris Newby, Another Biodesign Success: Researchers Develop Low-cost Medical Ventilators for Global Disasters, STAN. MED.: NEWS CTR. (Feb. 14, 2011), https://med.stanford.edu/news/all-news/2011/02/another-biodesign-success-researchers-develop-low-cost-medical-ventilators-for-global-disasters.html.
74 Sylvia Kuo et al., Natural History of Feeding Tube Use in Nursing Home Residents with Advanced Dementia, 10 J. AM. MED. DIRECTORS ASS’N 264 (May 2009), http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2733212/.
75 Id. PEG tubes were originally used on pediatric patients to avoid the problems of inserting feeding tubes through laparotomies. Id.
77 Id.
78 Id.
of the PEG tube, its developers opined that its use had far exceeded their intentions. In a 2006 news story about the use of PEG tubes for patients such as Terri Schiavo (a young woman, diagnosed as having been in a persistent vegetative state for many years), the developers of the PEG tube expressed concern. Their concern centered on the ethical dilemmas occasioned by the availability of PEG tubes for persistently vegetative patients who could not breathe or eat without life-sustaining tubes in place but who could now be kept alive for decades if connected to such tubes.

Further, there is growing consensus that feeding tubes are not recommended even for some patients with significant difficulty swallowing, and that they may not routinely improve outcomes. Studies have challenged the use of feeding tubes, for instance, for patients with advanced dementia. A variety of other end-of-life treatments and responses, including cardio-pulmonary resuscitation (“CPR”), continues to be provided to dying patients even in situations in which a patient’s treating clinicians view the care being provided as essentially futile.

As a result of the availability of such modes of treatment for dying patients (including ventilators, PEG tubes, and CPR), clinicians, patients, and family members of patients face a series of challenges about medical decision making for patients who lack the capacity to make their own decisions. Who should make such decisions and how they should be made have emerged as some of the most discomforting and controversial issues that have been occasioned by developments in treatment and medical technology that offer life-sustaining care to dying patients.

Patients, if capable, have the right to participate actively in medical

80 See infra Part IV.B.1.c.3.
81 Milicia, supra note 79.
82 See Kuo et al., supra note 74.
83 See id.
84 Gina Kolata, Murky Path in Deciding on Care at the End, N.Y. TIMES (Feb. 23, 2010), http://query.nytimes.com/gst/fullpage.html?res=9D04E1DF173AF930A157510C0A9669D8B6 3. In ICUs, it is not unusual to find patients given aggressive care even though the patient’s clinicians concluded days or even weeks earlier that the treatment would not return the patient to health. Id. (quoting Dr. Paul R. Helft, an oncologist at the Indiana University School of Medicine). On the other hand, aggressive care, including CPR for patients almost certain to die with or without CPR can offer emotional support to survivors who believe that “everything” was done for their loved one. Id. Such care is for families (or even sometimes for clinicians), not for patients, and may even substitute for care that would better serve a patient’s survivors. Id. (referring to comments by Dr. Robert Truog).
decisions about their care. Many dying patients as well as patients diag-
osed as persistently vegetative, however, are without capacity or have
diminished capacity to make medical decisions. The majority of court
cases involving end-of-life decision making have been occasioned by
disputes between a patient’s loved ones and health care providers or
among a patient’s loved ones.

IV. SOCIAL AND LEGAL RESPONSES TO DEATH AND DYING

The law’s responses to decision making for patients without capaci-
ty grew out of the jurisprudence of informed consent, implemented in
the last three decades of the twentieth century. The law has struggled to
shape appropriate responses for patients without capacity. This Part re-
views the development of legal responses to decision making for patients
who lack the capacity to make their own decisions.

A. Informed Consent and Patient Autonomy

Development of the informed consent doctrine followed from the
increasingly important notion in the last decades of the twentieth century
that the physician-patient relationship should reflect patient autonomy
and individuality at least as much as physician authority. More than a
half-century earlier, the kernel of the informed consent doctrine was
shaped by Judge (later Justice) Cardozo in a case in which he obligated
physicians to obtain a patient’s consent before operating on that pa-
tient. Judge Cardozo’s decision in Schloendorff did not require the pa-
tient’s clinicians to provide her with information about her condition and
about the care recommended. The decision offered an assessment of

85 See, e.g., In re Quinlan, 355 A.2d 647, 655 (N.J. 1976) (allowing the father of a wom-
an in persistent vegetative state to make medical decisions, including decision to terminate ventilator care, for his daughter).
86 See, e.g., Schiavo ex rel. Schindler v. Schiavo, 403 F.3d 1223 (11th Cir. 2005). The
case of Terri Schiavo is discussed infra Part IV.B.3.
87 At about the same time, the doctrine of informed consent became central to any effort
to conduct ethical biomedical research involving human subjects. See ALBERT R. JONSEN,
THE BIRTH OF BIOETHICS 334-35 (1998); Jay Katz, Human Experimentation and Human
Rights, 38 ST. LOUIS U. L.J. 7, 15 (1994); see also Janet L. Dolgin, The Evolution of the “Pa-
tient”: Shifts in Attitudes About Consent, Genetic Information, and Commercialization in
88 Schloendorff v. Soc’y of N.Y. Hosps., 105 N.E. 92, 93 (N.Y. 1914), overruled by Bing
v. Thunig 143 N.E.2d 3 (N.Y. 1957). Schloendorff was later overruled but the opinion ex-
pressed by Justice Cardozo helped spur the development of the informed consent doctrine.
89 See id. at 95.
the value of patient consent, however, that later became important in the development of the informed consent doctrine. Judge Cardozo intoned: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent, commits an assault, for which he is liable in damages."90

The notion gained little attention for over four decades. Then in 1957, a California court used the term “informed consent,” apparently for the first time in reference to the medical arena.91 The court required physicians to provide patients with “facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.”92

Fifteen years passed before courts and legislatures formulated concrete rules for determining the scope of the informed consent requirement. Canterbury v. Spence,93 decided in 1972 by a federal court, offered a broad interpretation of the informed consent doctrine.94 After Canterbury, courts95 and legislatures96 throughout the nation institutionalized the notion that a patient’s consent to medical care must reflect autonomous choice, deemed impossible unless the patient has been informed about the scope and implications of his or her health condition

90 Id. at 93.
92 Id. In distinction with later rules about informed consent, the Salgo court significantly limited the reach of its rule. The court stressed the significance of physician “discretion” to withhold information. Id. Jay Katz noted an inconsistency between the rule and its qualification. The rule, as qualified, Katz explained, imposed an impossible obligation on doctors to reveal all relevant facts and to withhold facts that could be upsetting to patients. See Jay Katz, Informed Consent—A Fairy Tale? Law’s Vision, 39 U. Pitt. L. Rev. 137, 138 (1977).
94 Id. at 787. In the same year in which the circuit court for the District of Columbia decided Canterbury v. Spence, the California Supreme Court reached a similar conclusion in another informed consent case. See Cobbs v. Grant, 502 P.2d 1, 10–11 (Cal. 1972). In Cobbs, the California court required physicians to give patients information on which a consent or refusal could be predicated and concluded that a jury (without need for expert testimony on the informed consent issue) was positioned to decide whether the information communicated to the patient by the physician was adequate. Id.
96 See, e.g., N.Y. PUB. HEALTH LAW § 2805-d (McKinney 2015) (limiting the right of action to recover for medical, dental, or podiatric malpractice based on a lack of informed consent).
and about the care being recommended. 97

B. Respecting Patient “Autonomy”: Patients Without Capacity

The informed consent doctrine rests on the presumption that a basic respect owed to patients obligates health care professionals to inform a patient about his or her medical condition and about recommended medical tests and treatments before seeking patient consent to care. 98 It predicates implementation of care on patients’ informed agreement. 99 The presumption that guided development of the informed consent doctrine cannot be applied easily to the situation of patients who lack decision-making capacity.

Yet, soon after the law clearly framed the informed consent doctrine, courts faced with cases involving very ill patients without capacity or permanently unconscious patients crafted an alternative response that paid homage to the informed consent doctrine while re-shaping its parameters for application to these patient populations. This response depended on the authorization of surrogate decision makers who were directed to effect the principal’s wishes where those had been delineated or to act in the principal’s best interest in cases in which the principal had not expressed his or her preferences for health care decisions relevant to the actual medical situation that pertained.

Much of this law was voiced by judges before it was entertained by legislatures. In addressing areas of life that implicate significant social challenges—disputes, for instance, about end-of-life care or care for persistently vegetative patients as well as disputes about a variety of domestic matters, including those occasioned by reproductive technology—courts often render decisions before legislators respond adequately or at all. 100 There are many reasons for this. Among them, courts do not generally have the option, enjoyed to a greater extent by legislators, of postponing consideration of controversial matters. 101

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97 Well-recognized exceptions to the requirement that patients consent to care before it is provided include emergency situations. Canterbury, 464 F.2d at 788–89.
99 Id. at 86.
100 In such cases, especially those involving disputes occasioned by reproductive technology, judges often implore state legislatures to entertain and provide statutory rules to channel the issues at stake. See, e.g., R.R. v. M.H., 689 N.E.2d 790, 797 (Mass. 1998); In re Marriage of Moschetta, 30 Cal. Rptr. 2d 893, 903 (Cal. Ct. App. 1994); In re Adoption of Baby Girl L.J., 505 N.Y.S.2d 813, 818 (N.Y. Surr. Ct. 1986).
101 Lloyd Duhaime, Delay in Reasons for Judgment: Justice Delayed is Justice Denied,
The first important decision by a state's highest court that responded to such a dispute involved the case of Karen Ann Quinlan in the New Jersey courts. *Quinlan*\(^{102}\) was decided in 1976, and is one among a number of cases that were occasioned by a request to discontinue life-sustaining care for a patient without capacity.\(^{103}\) A number of similar cases received widespread media attention in the last decades of the twentieth century and the early years of the twenty-first century.\(^{104}\) Perhaps because *Quinlan* was the first of these cases decided by a state's highest court, it brought public attention to the issues at stake.\(^{105}\) Even more, *Quinlan* was the first of a set of cases, including *Cruzan*\(^{106}\) and *Schiavo*\(^{107}\) that involved disputes regarding the continuation of life-sustaining care for someone in a persistent vegetative state. This Section will focus on three of these cases, that of Karen Quinlan, that of Nancy Cruzan, a Missouri case considered by the U.S. Supreme Court in 1990, and that of Terri Schiavo (decided in Florida in the early twenty-first century).\(^{108}\) Then the Section considers statutory responses to the dilemmas presented by end-of-life medical decision making.

1. *Quinlan* and its Context

The story of Karen Ann Quinlan was not the first disagreement made known to the public between the loved ones of an incapable, dying patient and the hospital in which that patient was being cared for. In 1957, a widow, publishing anonymously in the *Atlantic Monthly*, wrote about her husband's death in a hospital:

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\(^{103}\) See id. at 653.

\(^{104}\) In addition to *Quinlan*, see, for example, *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990); and *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378 (M.D. Fla. 2005). A suggestive, and potentially troubling, aspect of the three cases—though one beyond the scope of this Article—is the widespread media attention given to these cases (but not others), in that each of the three involved a young, middle-class, white woman, rendered vegetative in the prime of her life.


\(^{106}\) *Cruzan*, 497 U.S. 261.

\(^{107}\) *Schiavo*, 357 F. Supp. 2d 1378.

\(^{108}\) *Cruzan*, 497 U.S. 261; *Schiavo*, 357 F. Supp. 2d 1378; *Quinlan*, 355 A.2d 647.
As [the dead] fight for spiritual release, and are constantly dragged back by modern medicine to try again, does their agony augment? To those who stand and watch, this seems like a ghastly imposition against God’s will be done. Apparently there is no mercy which the family may bestow at such a time.\textsuperscript{109}

An editorial in the \textit{New England Journal of Medicine} in the same year recommended that all physicians read the anonymously authored \textit{Atlantic Monthly} essay.\textsuperscript{110} The editorial explained:

Today’s [medical school] graduate falls heir—and with no extra effort—to the immaculate, modern aseptic skills that can keep a diseased, half-dead, cancerous body alive, by intravenous nourishment and with the magic of penicillin and round-the-clock special nursing, so long that the doctor may emerge in the eyes of kin with little resemblance to the wise and understanding family physician of yesteryear.\textsuperscript{111}

The widow who wrote \textit{A Way of Dying}, to which the 1957 \textit{New England Journal of Medicine} editorial referred, did not initiate a legal case with the hope of changing the sort of care her dying husband was receiving.\textsuperscript{112} Her husband’s physician explained that continuing care, even for dying, delirious, or unconscious patients (viewed as “torture” by the anonymous author of the \textit{Atlantic Monthly} essay), was necessary to sustain life.\textsuperscript{113} When a nurse arrived, ready to give the author’s husband medication, the wife-author, though wanting to kick the nurse from the room, “staggered” out herself.\textsuperscript{114} “There was,” she explained, “nothing else to do.”\textsuperscript{115}

\textit{a. Karen Quinlan’s Story}

In contrast, the parents of Karen Quinlan, Joseph and Julia Quinlan, decided to seek judicial help in their effort to have life-sustaining treatment withdrawn from their daughter’s body. Joseph Quinlan, Karen’s father, sought a declaratory judgment against New Jersey, the county,

\textsuperscript{110} Id.
\textsuperscript{111} Id.
\textsuperscript{113} See id. at 11.
\textsuperscript{114} See id. (quoting \textit{A Way of Dying}, supra note 109).
\textsuperscript{115} See id. (quoting \textit{A Way of Dying}, supra note 109).
the treating physicians, and the hospital caring for Karen.\textsuperscript{116} He request-
ed appointment as his daughter's guardian and further, asked that the
court expressly grant him authority to "discontinu[e] . . . all extraordi-
nary means of sustaining the vital processes of his daughter."\textsuperscript{117}

The sudden failure of Karen Quinlan’s health occurred in the spring
of 1975 when Karen, then 21 years old, unexpectedly collapsed.\textsuperscript{118}
Friends called an ambulance immediately.\textsuperscript{119} By the time that the ambu-
lance arrived at a local hospital, Karen had been without oxygen for two
15-minute periods.\textsuperscript{120} The cause of her collapse was never discerned.\textsuperscript{121}
All parties agreed that Karen was completely unable to participate in de-
cisions concerning her care.\textsuperscript{122} Karen’s treating neurologist testified at
trial that he could not prognosticate about Karen’s future with certainty
but he was unaware of any treatment that would rehabilitate her and did
not “see how her condition [could] be reversed.”\textsuperscript{123}

The trial court relied on \textit{Kennedy Memorial Hospital v. Heston},\textsuperscript{124} a
1971 New Jersey Supreme Court decision, and rejected Joseph Quin-
lan’s claim, offered on behalf of his daughter that she enjoyed a constitu-
tional “right to die” and that this right supported his effort to have their
daughter’s life-sustaining care withdrawn.\textsuperscript{125} Judge Muir, writing for the
trial court, described all of the defendants as having viewed the potential
termination of Quinlan’s life support as “homicide and an act of eutha-

Further, Judge Muir grounded his decision to reject Joseph Quin-
lan’s petition on his understanding of the role of the physician.\textsuperscript{127} He ex-
plained:

\begin{quote}
There is a higher standard, a higher duty, that encompasses the uniqueness of
human life, the integrity of the medical profession and the attitude of society
toward the physician, and therefore the morals of society. A patient is placed,
or places himself, in the care of a physician with the expectation that he (the
\end{quote}

\begin{itemize}
\item[\textsuperscript{117}] \textit{Id.} Although Karen received nutrition through a naso-gastric tube, no request seems
ever to have been made to terminate that care. \textit{Id.} at 808.
\item[\textsuperscript{118}] \textit{Id.} at 806.
\item[\textsuperscript{119}] \textit{Quinlan}, 348 A.2d at 806.
\item[\textsuperscript{120}] \textit{Id.}
\item[\textsuperscript{121}] \textit{Id.}
\item[\textsuperscript{122}] \textit{Id.}
\item[\textsuperscript{123}] \textit{Quinlan}, 348 A.2d at 811.
\item[\textsuperscript{124}] 279 A.2d 670 (N.J. 1971).
\item[\textsuperscript{125}] \textit{Quinlan}, 348 A.2d at 814.
\item[\textsuperscript{126}] \textit{Id.}
\item[\textsuperscript{127}] \textit{Id.} at 818.
\end{itemize}
physician) will do everything in his power, everything that is known to modern medicine, to protect the patient’s life. He will do all within his human power to favor life against death.\footnote{129}

Accordingly, Judge Muir placed great importance on the view of Dr. Morse, Karen’s neurologist, that “medical tradition” could not “justify” the removal of Karen’s ventilator.\footnote{129}

The trial court’s response to Karen’s pre-incapacity assertion, reported to the court by Karen’s mother, that she would not want to be kept alive in a situation similar to the one in which she existed, deserves note.\footnote{130} The court essentially interpreted Karen’s reported preference as the musings of a young woman (20 years old at the time), who was “full of life” and had not seriously contemplated her own death.\footnote{131} Judge Muir’s view in Quinlan is significant as an historical matter. It suggests the remarkable shift in social and legal views of advance care planning (views that gainsay Judge Muir’s position) that emerged even as soon as the state supreme court’s decision in Quinlan.

\textit{b. Quinlan in New Jersey’s Highest Court}

Justice Hughes, writing for the New Jersey Supreme Court,\footnote{132} noted early in his opinion that Karen’s physicians as well as experts who testified at trial all agreed that to withdraw respiratory support from Karen would conflict with “medical practices, standards and traditions.”\footnote{133} Yet, Justice Hughes, in a remarkable decision reflecting, and perhaps shaping, responses in the decades to follow rather than those extant when he wrote \textit{Quinlan}, named Karen’s father as guardian for his daughter and expressly provided authority for him to request termination of respiratory support for Karen.\footnote{134} That authority was conditioned by Joseph Quinlan’s obtaining the agreement of the hospital’s “Ethics Committee’ or like body” and by the consensus of Karen’s physicians that there was “no reasonable possibility” of her “emerging from her . . . comatose condition to a cognitive, sapient state.”\footnote{135}

\begin{footnotes}
\item[128] Id. (footnote omitted).
\item[129] \textit{Quinlan}, 348 A.2d at 818.
\item[130] \textit{Id}.
\item[131] \textit{Id}.
\item[132] \textit{In re Quinlan}, 355 A.2d 647 (1976).
\item[133] \textit{Id} at 655.
\item[134] \textit{Id} at 671.
\item[135] \textit{Id} at 672.
\end{footnotes}
Justice Hughes’ decision conflicted with the almost unanimous view among physicians at the time regarding the withdrawal of life-sustaining care. It was not considered acceptable medical practice to withdraw life support from a patient who was not brain dead. Dr. Sidney Diamond, an expert witness for the State, testified that withholding or withdrawing respiratory support from Karen was outside the parameters of ethical medical practice. Dr. Morse, Karen’s treating neurologist agreed. Yet, when the Quinlans, who were practicing Catholics, consulted with their priest and with the hospital’s chaplain, both assured them that their Church’s tenets supported their wish to have Karen’s respiratory support terminated.

Justice Hughes affirmed that were Karen competent, she would have enjoyed the right to request termination of life-sustaining care. Fourteen years later, that position was “assumed” by the U.S. Supreme Court in *Cruzan v. Dir., Mo. Dep’t of Health.* Further, Justice Hughes noted—while at the same time acknowledging that testimony about previous conversations between Karen and her friends did not provide probative evidence regarding Karen’s views on life-sustaining care—he was absolutely sure that were Karen competent just long enough to assess her situation and her prognosis, she would ask that respiratory support be discontinued. Thus, he concluded that Karen’s privacy right to refuse care would be vitiated were it not transferred to her father, whom the court viewed as a fit guardian for his daughter.

Karen’s physicians testified at trial that she would likely not survive for long without the respirator. After Judge Hughes’ decision, Karen’s father authorized withdrawal of Karen’s respiratory support. Karen

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136 In *Quinlan,* itself, all of Karen’s doctors as well as the hospital and the state, opposed Joseph Quinlan’s effort to have life-sustaining care for his daughter withdrawn. See *Quinlan,* 355 A.2d 647.
137 *Id.* at 656.
138 *Id.* at 657.
139 *Id.*
140 *Quinlan,* 355 A.2d at 658. The court noted that it entertained the views of the Catholic Church only insofar as those views bore on Joseph Quinlan’s “character, motivations and purposes as relevant to his qualification and suitability as guardian.” *Id.* at 660.
141 *Id.* at 663.
143 *Quinlan,* 355 A.2d at 663.
144 *Id.* at 664, 671.
145 *Id.* at 655.
was successfully weaned from the respirator and lived for almost a decade. She died of pneumonia in 1985.

c. Confusion About the Meaning of Death: "Brain Death"

Initially, Joseph Quinlan’s petition to the New Jersey Superior Court for appointment as his daughter’s guardian described Karen as already dead. Later, he acknowledged that Karen “[was] not dead ‘according to any legal standard recognized by the State of New Jersey.’” The Quinlan case commenced less than a decade after an Ad Hoc Committee at the Harvard Medical School defined “brain death” as an alternative to cessation of respiration and cardiac activity for establishing death. The criteria delineated in the Ad Hoc Committee’s report for establishing brain death included the absence of breathing, movement, and reflexes that could be elicited, as well as a flat electroencephalogram (repeated 24 hours after the first test, with no change). Yet, the Ad Hoc Committee’s delineation of “brain death” left many people confused.

Justice Hughes expressly noted in Quinlan that new technology had obscured traditional understandings of death. Although Karen was not brain dead, the possibility of declaring someone dead whose heart continued to pump blood (albeit with technological assistance) had opened up a slew of possibilities heretofore not easily imaginable. Not only, for instance, did the parents’ original petition in Quinlan contend that Karen was dead, but others, reviewing the Quinlans’ story, have agreed with that contention. Arguing that Karen should have been declared dead before the respirator was withdrawn, one critic explained:

The currently accepted criteria of death, one must conclude, are underin-

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148 id.
150 id.
152 id. at 337–38.
elusive. The influential Harvard Report sanctions pronouncement of death once there is irreversible coma, which exists, according to the Report, when there is no discernible central nervous system activity. But if we accept that the essential qualities of life are cognitivity and sapience, our criteria for death may be broadened. Death, we may say, shall be pronounced when there is no longer any reasonable possibility of a present or future cognitive, sapient state, whether or not the nervous system shows signs of activity.\footnote{\ref{fn:155}}

2. \textit{Cruzan}

In 1990 the United States Supreme Court reviewed a Missouri case that involved another young woman who became persistently vegetative—in Nancy Cruzan's case, the result of an automobile accident.\footnote{\ref{fn:156}} Nancy's parents, much like Karen's parents before them, requested that life-sustaining care be withdrawn.\footnote{\ref{fn:157}} Missouri courts required clear and convincing evidence that a patient without capacity would have wanted the withdrawal of life-sustaining care before such care could be withdrawn.\footnote{\ref{fn:158}} The Missouri courts read that standard stringently.\footnote{\ref{fn:159}}

Unlike Karen Ann Quinlan, Nancy was able to breathe without respiratory support.\footnote{\ref{fn:160}} Nancy's parents asked that her feeding tube be withdrawn.\footnote{\ref{fn:161}} The hospital sought court approval for the withdrawal.\footnote{\ref{fn:162}} Invoking a state policy "favoring life," the Missouri Supreme Court, overruling the trial court decision, held against Nancy's parents.\footnote{\ref{fn:163}} The Cruzans challenged the Missouri decision in the United States Supreme Court.\footnote{\ref{fn:164}}

\textit{Cruzan} is the only Supreme Court case focused on the right of a surrogate decision maker to refuse end-of-life care, and the implications of its holding have been difficult to interpret. The case has probably been most important for the Court's "assumption" that capable adults have the right to refuse care or to have life-sustaining care withdrawn.\footnote{\ref{fn:165}}
Even the implications of that assertion, however, were not transparent insofar as the Court "assumed," but did not expressly declare, a competent adult’s right to refuse life-sustaining care.

In any event, the issue at stake in the *Cruzan* case went beyond any assertion about the right of a capable patient to participate in his or her medical decisions in that *Cruzan* involved the right of a surrogate decision maker to enjoy the same authority that a capable patient enjoys.\(^{166}\)

Here, the Court sided with Missouri, against Nancy’s parents.\(^{167}\)

We think it self-evident that the interests at stake in the instant proceedings are more substantial, both on an individual and societal level, than those involved in a run-of-the-mine civil dispute. But not only does the [clear and convincing evidence] standard of proof [set by Missouri] reflect the importance of a particular adjudication, it also serves as “a societal judgment about how the risk of error should be distributed between the litigants.”\(^{168}\)

The Court’s decision in *Cruzan* permits, but does not require, states to demand clear and convincing evidence\(^{169}\) of a patient’s pre-incompetency wishes before permitting a surrogate to authorize withdrawal of life-sustaining care. Interestingly, a subsequent proceeding in Missouri, brought by Nancy’s parents on the basis of new evidence about Nancy’s pre-incompetency wishes, resulted in a Missouri court finding that the requirements of the state’s clear and convincing evidence standard had been met.\(^{170}\) Subsequently, Nancy’s feeding tube was withdrawn.\(^{171}\) She died in late 1990.\(^{172}\)

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\(^{166}\) *Cruzan*, 497 U.S. at 280.

\(^{167}\) *id.* at 265.

\(^{168}\) *id.* at 283.

\(^{169}\) *id.* at 283-84. Although a number of states apply a standard of clear and convincing evidence to disputes about the withdrawal of life-sustaining care, only two—Missouri and New York—traditionally interpreted the standard with great stringency. New York’s law changed dramatically in 1990 with passage of the Health Care Proxy Act, 1990 N.Y Sess. Laws 752 (McKinney) (codified as N.Y. PUB. HEALTH LAW § 2981 (McKinney 2015)), and again in 2010 with passage of the Family Health Care Decisions Act (FHCDA), 2010 N.Y. Sess. Laws ch. 8 (McKinney) (codified as N.Y. PUB. HEALTH LAW § 2994-a et seq. (McKinney 2015)).


\(^{172}\) *id.*; Lawlor, *supra* note 170, at 76 n.65.
3. Schiavo

The story of Terri Schiavo resembles those of Karen Quinlan and Nancy Cruzan in that all of them were young, healthy, white, middle-class women, and all of them were in their twenties when they entered into a persistent vegetative state from which they never emerged. In two of the cases—those involving Karen Ann Quinlan and Terri Schiavo—the cause was never clarified with certainty.173 Terri Schiavo’s story, however, departs from that of Karen Ann Quinlan and Nancy Cruzan in that the dispute that brought the case to court was between family members—in particular, Terri’s parents on one side and her husband on the other—rather than between family members and the patient’s health care providers.174

State and federal courts entertained a variety of questions occasioned by the dispute between Terri Schiavo’s parents and her husband over a period of many years before Terri’s death in 2005.175 The Schiavo story garnered significant public attention, especially in the few years before Terri’s death.176 Unlike the Quinlan case, and more like the case of Nancy Cruzan, the legal saga that defined Terri Schiavo’s last twelve years of life, made little new law.177 The Schiavo narrative, however, provides a view of the trauma experienced by family, clinicians, and society more broadly occasioned by disputes about medical decision making for patients without capacity.

173 It was clear that Terri Schiavo suffered a cardiac arrest, perhaps due to a potassium imbalance. See Schiavo Timeline, Part 1, U. MIAMI: ETHICS PROGRAMS, http://www.miami.edu/index.php/ethics/projects/schiavo/schiavo_timeline/ (last visited Jan. 7, 2016). The cause of her cardiac arrest, however, has been disputed. A website set up by the Schindlers, Terri’s parents, characterized her collapse as “a mysterious cardio-respiratory arrest for which no cause has ever been determined.” See Terry Schiavo’s Story, TERRY SCHIAVO LIFE & HOPE NETWORK, http://www.lifeandhope.com/terri_schiavo (last visited Jan. 22, 2016); see also MARK FUHRMAN, SILENT WITNESS: THE UNTOLD STORY OF TERRI SCHIAVO’S DEATH, 225–26 (2005) (suggesting that Michael Schiavo may have borne responsibility for Terri’s collapse).


177 Because the Schiavo case—though it was entertained in federal and state courts—made little new law, this section focuses on the story. Relevant legal documents as well as a timeline of the Schiavo story can be found online at Schiavo Timeline, Part 1, supra note 173, and Schiavo Timeline, Part 2, supra note 175.
In 1990, Terri Schindler Schiavo, then 26 years old and married since the age of 20 to Michael Schiavo, suffered a cardiac arrest and entered into a persistent vegetative state. She was unable to eat or drink; a feeding tube provided Terri with nourishment and hydration. Terri was, however, able to breathe without respiratory support. Michael Schiavo, as Terri’s husband, became her legal guardian and medical decision maker under Florida law. For a few years, Michael cooperated with Terri’s parents in providing care for Terri. Then, in 1993, relationships soured, perhaps as the result of disagreements concerning money. By the end of the decade, Michael Schiavo sought to have Terri’s life-sustaining care withdrawn. Michael contended that he wanted to accomplish only what Terri herself would have wanted. The story, however, was complicated. Even as Michael declined to yield his role as Terri’s guardian and requested withdrawal of life-sustaining care for Terri, he was cohabiting with another woman, with whom he had two children.

In 2000, Judge Greer for a Florida trial court concluded that Terri’s statements before she became incompetent provided “clear and convincing evidence” that she would choose, in the circumstances in which she existed at the time of the legal case, to discontinue life-sustaining care. Thus, he sided with Michael, Terri’s husband, authorizing the withdrawal of Terri’s feeding tube. Terri’s parents appealed Judge Greer’s decision, but the Florida appellate court affirmed it. Before the case concluded with Terri’s death in 2005, the Schiavo-Schindler dispute was entertained by every level of the Florida court system and by several

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179 Id.
180 See In re Guardianship of Schiavo, 780 So. 2d 176, 177 (Fla. Dist. Ct. App.), review denied, 789 So. 2d 348 (Fla. 2001).
181 See Schiavo Timeline, Part I, supra note 173.
183 Id. Michael began a large malpractice action against physicians who had been treating Terri before her collapse. Id. About a million dollars was awarded between Terri and Michael. Id.
184 See Schiavo, 780 So. 2d at 177.
188 Id. at *6–7.
189 Schiavo, 780 So. 2d at 177.
federal courts, the U.S. Congress, and the nation’s President. Beyond all else, the Schiavo tale and the legal battles that accompanied it suggested the extent of confusion within the law and society about how best to handle disputes about the withdrawal of life-sustaining care. In March 2005, five years after Judge Greer found clear and convincing evidence that Terri would not have wanted to be kept alive in the condition she was in, Terri’s feeding tube was removed.

4. The Lessons of Quinlan, Cruzan, and Schiavo

Quinlan made new law and provided a model for states ready to concede that life-sustaining care, once inserted, could be removed prior to the patient being declared dead from causes not related to the withdrawal of that care. Cruzan is important because the Supreme Court entertained the case, but the Court’s ruling provided little guidance to the nation about how the law might best handle such cases. Neither Judge Greer’s 2000 decision to order the withdrawal of Terri Schiavo’s feeding tube nor the many judicial proceedings, legislative responses, and ex-

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190 See Schiavo Timeline, Part I, supra note 173; see also Schiavo Timeline, Part 2, supra note 175.


192 The feeding tube had been removed twice previously. Each time a court order led to the withdrawal of the feeding tube. Schiavo Timeline, Part I, supra note 173. On March 31, 2005, almost two weeks after removal of Terri’s feeding tube, she passed away. Terry Schiavo’s Story, supra note 173.

193 But see In re Conroy, 486 A.2d 1209, 1228–30 (N.J. 1985) (distinguishing Quinlan from case of patient who could “interact with [her] environment to a limited extent, but whose mental and physical functioning is severely and permanently impaired and whose life expectancy, even with the treatment, is relatively short” and finding that court was “in error in Quinlan” in ignoring “evidence of statements that Ms. Quinlan made to friends concerning artificial prolongation of the lives of others who were terminally ill”).

194 See, e.g., Schiavo ex rel. Schindler v. Schiavo, 357 F. Supp. 2d 1378 (M.D. Fla. 2005) (denying motion for temporary restraining order); Schindler v. Schiavo, 900 So. 2d 544 (Fla. 2005) (denying all writs jurisdiction); In re Guardianship of Schiavo, 916 So. 2d 814 (Fla.
ecutive acts that followed re-shape state law. Further, they did not re-
shape the nation's understanding of how the law might respond effec-
tively and wisely to the issues at stake. The case came to an end only in
2005 when the U.S. Supreme Court refused to review\textsuperscript{195} the Eleventh
Circuit's decision that facilitated the order to withdraw Terri Schiavo's
care.\textsuperscript{196}

Although Schiavo did not re-shape Florida laws regarding end-of-
life decision making, the case was extraordinarily important in other re-
gards. In particular, it drew public attention to the challenge presented
by a patient—here a young woman—who entered into a persistent vege-
tative state without having completed an advance directive and without
having engaged in serious, in-depth conversations with family members
about her medical preferences should she need care and lack the capacity
to make her own decisions. The lessons of Terri's case apply equally to
patients suffering from serious medical conditions but incapable of mak-
ing their own medical decisions.

Karen Quinlan and Nancy Cruzan died before the internet exist-
ed.\textsuperscript{197} Terri Schiavo did not. Terri's story, through blogs, photos, news
stories, and comments, populated the internet for the last several years of
her life and continues to garner attention.\textsuperscript{198} The legal issues in the case,
as stated by a Florida appellate court, could be described simply. The
implications of the issues, however, have been extraordinarily challeng-
ing. Judge Altenbemd for a Florida appellate court wrote:

\begin{quote}
In the final analysis, the difficult question that faced the trial court was
\end{quote}

\textsuperscript{196} Schiavo ex rel. Schindler v. Schiavo, 404 F.3d 1270 (11th Cir.), reh'g denied, 404
F.3d 1282 (11th Cir. 2005).
\textsuperscript{197} The World Wide Web was available to the public in 1991. Internet History: Timeline,
INTERNET HALL FAME, http://www.internethalloffame.org/internet-history/timeline (last visit-
\textsuperscript{198} See, e.g., TERRI SCHIAVO LIFE & HOPE NETWORK, http://www.lifeandhope.com/ (last
visited Jan. 22, 2016) (website about Terri now maintained by her brother in Pennsylvania); Sandy
Bauers, Schiavo Controversy Returns to Pa., Along with Palin, PHIL. INQUIRER (Apr.
4, 2013), http://articles.philly.com/2013-04-04/entertainment/38251788_1_vegetative-patient-
sarah-palin. A decade after Terri's death, the media still refers to the role of then-Governor of
Florida and presidential hopeful, Jeb Bush in the Schiavo case. See, e.g., Michael Putney,
Opinion, First Round Goes to Bush, MIAMI HERALD (Feb. 3, 2015), http://www.miamiherald.com/opinion/op-ed/article9145133.html (noting that "doctrinaire liberals" dislike Jeb Bush because of his attempt to have the state intervene in the Schiavo
case on the Schindlers' side).
whether Theresa Marie Schindler Schiavo, not after a few weeks in a coma, but after ten years in a persistent vegetative state... would choose to continue the constant nursing care and the supporting tubes in hopes that a miracle would somehow recreate her missing brain tissue, or whether she would wish to permit a natural death process to take its course and for her family members and loved ones to be free to continue their lives. After due consideration, we conclude that the trial judge had clear and convincing evidence to answer this question as he did.\textsuperscript{199}

C. Legislative Responses

In Quinlan, New Jersey Supreme Court Chief Justice Hughes reported that at the time (1976) there was a "relative paucity of legislative and judicial guides and standards" relating to the matters at issue in the case.\textsuperscript{200} Soon, however—and perhaps in some part because of Justice Hughes' Quinlan decision—states began widely to promulgate laws pertaining to advance care planning. Generally framed as end-of-life law, a body of rules and legal options developed within the states.\textsuperscript{201}

Quinlan, Cruzan, and Schiavo, all involving young persons, make it clear that planning for medical decisions, should one become ill and incapable of making decisions, is not a process that should be reserved only for elderly or sick people. Certainly, old people are more likely to die than younger people. Young people, however, do die; they may fall into persistent vegetative states; and they may be seriously ill—but not terminally ill—and in need of surrogate decision making regarding their care. Advance care planning should be entertained by every adult.\textsuperscript{202}

\textsuperscript{199} In re Guardianship of Schiavo, 780 So. 2d 177, 180 (Fla. Dist. Ct. App. 2001).
\textsuperscript{200} In re Quinlan, 355 A.2d 647, 667 (N.J. 1976).
\textsuperscript{202} Since elderly people as a group are more likely than younger people to face serious illness and death, advance care planning becomes an even more essential matter for the nation as its population ages. In 1900, 100,000 people in the U.S. were 85 or older. In 2012, there were 5.9 million people in that age group. And by 2050, it is expected that 18 million people will be 85 or older. See HOFFMAN, supra note 11, at xv. The extended years of life enjoyed by the population as a whole are often accompanied by chronic health conditions, including coronary disease, renal disease, lung conditions, and cancer. Id. at xvi.
Federal law requires health care facilities that accept Medicare and Medicaid patients to inform patients about advance care planning and about the opportunity to complete advance directives. 203 The details of the process follow from the laws of the relevant state. By the beginning of the twenty-first century, every state provided by statute for some form of advance care planning. 204 Broadly, these laws provide for competent adults to name a surrogate decision maker and to provide instructions for medical care should they lose capacity to make medical decisions. 205 These laws, however, do not mandate advance care planning. 206 In general, state laws direct a surrogate to make decisions in harmony with the principal’s pre-incompetency preferences and wishes or, if those are not clear, in harmony with the principal’s best interests. 207 The best-interest guideline, presumptively objective, 208 offers little concrete assistance. But it does offer a means for reaching a decision in cases in which there is inadequate or no evidence about a no-longer-competent patient’s pre-incompetency preferences. 209


205 The specifics vary. For instance, some states provide for appointment of a durable power of attorney. See, e.g., ALASKA STAT. ANN. § 13.52.300 (West 2014) (providing for appointment of a durable power of attorney); see also, ALASKA DEPARTMENT OF HEALTH & SOCIAL SERVICES, ADVANCE DIRECTIVE FOR HEALTH CARE FORM, http://dhss.alaska.gov/dph/Dir/Department/Documents/advancedirective.pdf (last visited Jan. 22, 2016). Others provide, for instance, for health proxies, see, e.g., ALA. CODE § 22-8A-4(h) (West 2015), or “surrogates,” see, e.g., FLA. STAT. ANN. § 765.202 (West 2015). By statute, Florida prescribes a form to appoint a surrogate. Id. § 765.203.

206 Noah, supra note 204, at 9.

207 Cantor, supra note 204, at 189.


209 The first end-of-life laws provided for people, while competent, to create “living wills.” It was passed in California in 1976. See Jennison, supra note 201, at 304. A second type of law aimed at providing for end-of-life decision making for people without capacity appeared about a decade later and followed the model of a power of attorney. Powers of attorney do not survive the principal’s incompetency. Thus, states created durable powers of attorney that would authorize surrogates to make decisions for incapacitated patients. See Sabatino,
An additional set of state laws identifies default surrogate decision makers for patients without advance directives. The Uniform Health-Care Decisions Act (UHCDA), presented by the Uniform Law Commission in 1993, delineates default surrogate decision makers in order of priority for patients who have not identified a surrogate and who lack capacity.\textsuperscript{210} The act lists a patient’s spouse as the privileged decision maker; if the patient does not have a spouse, the act identifies, in this order, an adult child, a parent, and then an adult sibling.\textsuperscript{211} If none of these is available, an adult who cared about the patient and who is familiar with his or her health care preferences is authorized to serve as a surrogate decision maker.\textsuperscript{212} Only six states have adopted the UHCDA.\textsuperscript{213} Most states and the District of Columbia, however, now provide for default decision makers, more or less reflecting the order of priority noted in the UHCDA.\textsuperscript{214}

Promulgated over several decades, states’ end-of-life laws\textsuperscript{215} provide a legal frame for the appointment of surrogate decision makers; facilitate identification of decision makers in cases in which a patient had


\textsuperscript{211} Id.

\textsuperscript{212} Id.

\textsuperscript{213} These states are Alaska, Hawaii, Maine, Mississippi, New Mexico and Wyoming. Id.


\textsuperscript{215} The laws considered here in Part IV.C are referred to as “end-of-life” laws because they have been promulgated with end-of-life issues in mind. See Lois Shepherd, The End of End-of-Life Law, 92 N.C. L. REV. 1693, 1695–96 (2014) (noting that these statutes concern issues regarding end-of-life decision making).
not designated a surrogate while competent; encourage the provision of
pre-incompetency instructions about preferences and wishes regarding
medical care, including end-of-life care; and provide for the refusal of
care, including cardio-pulmonary resuscitation in hospital and non-
hospital settings. With such laws, states have attempted to ensure that
advance care plans, if documented pursuant to law, will be followed.\textsuperscript{216}

This body of law—though important to the facilitation of advance
care planning—has occasioned several concerns. Commentators have
noted the discomfort provoked by the subjunctive at the center of most
advance care planning (e.g., “were I ill and incapable, I would
want . . .”). The presumption that the preferences set forth by the once-
capable patient harmonize with what the now-ill, incompetent patient
would want were he or she offered a moment of lucidity for decision
making cannot easily be sustained.\textsuperscript{217} That presumption harmonizes
poorly with the notion of autonomous choice—the putative rationale for
the movement to encourage advance care planning.\textsuperscript{218} Further, the com-
pletion of advance directives does not always preclude disputes among
family members or between surrogates and clinicians.\textsuperscript{219} Despite such
concerns, there is a continuing need for advance care planning that in-
cludes “the inherent and immediate benefit to the individual of thinking
about and executing an advance directive.”\textsuperscript{220}

Even more, advance care planning has been only partially success-
ful because most adults do not complete advance directives or discuss
their health care preferences with loved ones and clinicians. Discussing
one’s own dying and death are discomforting topics for most people and
for their loved ones. In addition, advance care planning has been con-
flated, mistakenly, with physician-assisted suicide and euthanasia.

\textbf{D. Physician-assisted Suicide and Euthanasia: A “Slippery Slope”
or a Different Matter?}

This confusion—between advance care planning and physician-
assisted suicide and euthanasia—has burdened efforts to encourage peo-
ple to contemplate and discuss their medical wishes should they lose the

\begin{footnotes}
\item[216] See id. at 1696–97 (delineating the variety of names by which these forms are known
in the states).
\item[217] See, e.g., Steven R. Latham, \textit{Living Wills and Alzheimer’s Disease}, 23 QUINNIPIAC
\item[218] Noah, \textit{supra} note 204, at 12.
\item[219] See id. at 6–7.
\item[220] \textit{id.} at 7–8.
\end{footnotes}
capacity to make their own medical decisions. Moreover, it has created anxiety among many people about signing advance directives, as a practical matter. This is unfortunate in that advance care planning is an important component of good health care. Even more, it can obviate a patient’s interest in physician-assisted suicide or in euthanasia.

In 1997, the United States Supreme Court declined to find a constitutional right to physician-assisted suicide. This left the states free to choose whether to enact such laws. Oregon, Washington, and Vermont have legalized physician-assisted suicide. Physician-assisted suicide is also legal in Montana and New Mexico, as a result of court cases.

Claims grounded in ideological interests have clouded the matter. There is no evidence, however, that supports a link between advance care planning and physician-assisted suicide.

221 Sarah Palin’s “death panel” claim is illustrative. See infra Part V.A.1.
222 See, e.g., Jonathan Moreno, Who’s to Choose?: Surrogate Decisionmaking in New York State, 5 HASTINGS CTR. RPT., no. 1, Jan.–Feb. 2013, at 5 (noting concern about slippery slope should laws provide for withdrawal or withholding of life-sustaining care).
223 The confusion was fueled by claims from critics of health care reform that the government would use advance care planning to ration resources for elderly patients. See, e.g., Sarah Palin, Concerning the “Death Panels,” FACEBOOK (Aug. 12, 2009), https://www.facebook.com/note.php?note_id=116471698434; see also infra Part V (considering opposition to Medicare’s paying clinicians for holding conversations with patients about advance care planning). These claims were grounded on mistaken or self-consciously twisted information. See infra Section V.A.1. (considering claims that paying for advance care planning sessions constituted “death panels”).
226 See Death with Dignity Around the U.S., supra note 225 (noting that about half of the state legislatures are scheduled to consider the matter in 2015). No state in the U.S. provides for euthanasia. Id. A number of other countries also legalized physician-assisted suicide, and a few, including the Netherlands and Belgium, have legalized euthanasia. See, e.g., Termination of Life on Request and Assisted Suicide Act of 2002 (Neth.); Euthanasia Act of 2002 (Belg.). There is still controversy about laws that have legalized physician-assisted suicide and about their implications for public policy. In the states that have legalized physician-assisted suicide, however, there is no evidence of abuse. As of February 2015, 1,327 people in Oregon had filled prescriptions pursuant to the Death with Dignity Act. 859 patients died as a result of using these prescribed medications. See OR. PUB. HEALTH Div., OREGON’S DEATH WITH DIGNITY ACT–2014, (2014), https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf. The practice has been legal in Oregon for almost 20 years. The Oregon Health Department reports data showing that the practice is not common there and has not been abused. Since the statute’s implementation most of the patients who relied on it had cancer (68.6% in 2014). Over 2/3 were aged 65 or older; most (95.2%) were white, and 45.6% had a baccalaureate or higher degree. Id.
227 See infra Part V.
care planning and physician-assisted suicide or between physician-assisted suicide and euthanasia. The matters are distinct. In fact, advance care planning—by offering patients options for palliative and hospice care—can further the development of a medical setting that should diminish interest in physician-assisted suicide or euthanasia.

A good death, in the contemporary context, should not be confused with physician-assisted suicide. As John Arras wrote in the same year that Oregon legalized physician-assisted suicide:

[Physicians must learn how to really listen to their patients, to unflinchingly engage them in sensitive discussions of their needs and the meaning of their requests for assisted death, to deliver appropriate palliative care, to distinguish fact from fiction in the ethics and law of pain relief, to diagnose and treat clinical depression, and, finally, to ascertain and respect their patients' wishes for control regarding the forgoing of life-sustaining treatment.]

Such care, now routinely provided by hospice, does not involve the ingestion of lethal medication. Rather, it depends only on the discontinuance, at a patient's request (or at the request of a patient's surrogate) that aggressive care be discontinued so that patients "may take advantage of their next naturally occurring opportunity to die." Such requests, however, must be based on the patient's (or his or her surrogate's) understanding of the patient's medical situation and available treatment options. In most cases, that depends on patients having discussed their health care preferences with loved ones and clinicians before a medical crisis develops. This is more likely to occur if clinicians are reimbursed for the time devoted to such conversations. That reimbursement will make it clear that advance care planning can be an essential component of good health care.

V. PAYMENT FOR ADVANCE CARE PLANNING: A NATIONAL DEBATE

The American health care system generally reimburses clinicians and health care facilities for tests and examinations aimed at diagnosis of illness (and a few, such as mammography, aimed at early diagnosis), as well as for a patient's hospitalization and for procedures and medications

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229 Yale Kamisar, Are the Distinctions Drawn in the Debate about End-of-life Decision Making “Principled”? If Not, How Much Does it Matter?, 40 J.L. MED. & ETHICS 66, 67 (quoting JEANNE FITZPATRICK & EILEEN M. FITZPATRICK, A BETTER WAY TO DIE 41 (2009)).
provided by health care facilities. Far fewer funds are available to pay clinicians for attending to patient’s most pressing needs near the end of life than are available for continuing—often essentially useless—treatments. Dale Lupu has compared services generally considered reimbursable—"procedures, chemotherapy, clinic visits, emergency room"—with those generally not reimbursed or not reimbursed adequately given the needs of patients near the end of life—"caregiving, communication and pain control, home visits, and 24-hour on-call nursing." Patients would receive better health care were the latter set of services reimbursable.

Paying clinicians for time spent speaking with patients—as a general matter and with regard to end-of-life care, as a particular matter—would significantly increase patient satisfaction, inform patients about medical options, and enrich the patient-clinician relationship. In addition to its most obvious purpose (reimbursement for the time of a skilled professional), availability of payment for such conversations between patients and clinicians would categorize these conversations as a component of good health care (which they are). Yet, just that sort of suggestion—that Medicare pay clinicians to talk with patients about advance care planning—resulted in charges of governmental “death panels” and fueled unfounded patient concern about the government’s role under the bill that became the Patient Protection and Affordable Care Act.

A. Advance Care Planning and Fabricated Claims: Serving Partisan Political Ends

This Section details the 2009 proposal to pay clinicians for engaging in conversations about advance care planning with patients, and it details public responses to that proposal. Further it describes a Centers for Medicare and Medicaid Services (“CMS”) proposed regulation (released in July 2015 and finalized that November) to provide for such payments beginning in 2016. The matter is basic since willingness to pay for advance care planning consultations provides compelling evi-


dence of society’s commitment to meeting the needs of very sick patients and their families and, more important even, its commitment to a health care system that assumes that patients and clinicians should converse with each other about the patient’s health care.

1. Social Media: Defeating the Coverage Provision

A comment, posted on Facebook in August of 2009 by Sarah Palin (the 2008 Republican candidate for vice-president), inspired almost one-third of the nation to conclude that the Patient Protection and Affordable Care Act (“PPACA”), if promulgated, would sanction “death panels,” aimed at limiting care for the elderly. Palin’s Facebook comment alleged:

The Democrats promise that a government health care system will reduce the cost of health care, but as the economist Thomas Sowell has pointed out, government health care will not reduce the cost; it will simply refuse to pay the cost. And who will suffer the most when they ration care? The sick, the elderly, and the disabled, of course. The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care. Such a system is downright evil.

A few days later, again on Facebook, she elaborated on her earlier post.

Yesterday President Obama responded to my statement that Democratic health care proposals would lead to rationed care; that the sick, the elderly, and the disabled would suffer the most under such rationing; and that under such a system these “unproductive” members of society could face the prospect of government bureaucrats determining whether they deserve health care. The President made light of these concerns.

The “death panel” claim—or myth, as some have referred to it—seems to have been first voiced in public media not by Palin, but, a

235 See Palin, supra note 223.
236 Nyhan, supra note 233, at 10.
month before Palin’s Facebook comments, by Elizabeth McCaughey (a former New York lieutenant government). McCaughey, interviewed in July 2009 on former Senator Fred Thompson’s radio program, opined about the health reform bill in Congress in 2009.\(^{237}\)

And one of the most shocking things I found in this bill, and there were many, is on Page 425, where the Congress would make it mandatory—absolutely require—that every five years, people in Medicare have a required counseling session that will tell them how to end their life sooner, how to decline nutrition, how to decline being hydrated, how to go in to hospice care. And by the way, the bill expressly says that if you get sick somewhere in that five-year period—if you get a cancer diagnosis, for example—you have to go through that session again. All to do what’s in society’s best interest or your family’s best interest and cut your life short. These are such sacred issues of life and death. Government should have nothing to do with this.\(^{238}\)

McCaughey’s central assertions, all false, were broadcast widely and provided fuel for the claim that the PPACA would have devastating consequences for Americans’ health care. Palin’s Facebook post that the provisions at issue would create “death panels”\(^{239}\) provided additional fuel for PPACA opponents. The “death panel” claim, though based on a serious misreading of the proposed law, resonated with large segments of the public, in part because it echoed concerns already in the air that Obama’s health reform efforts would result in rationing, especially for elderly and other vulnerable people.\(^{240}\)

A key claim at the center of the “death panel” claim—the assertion that counseling for Medicare recipients about advance care planning would be mandatory every five years or perhaps more often—was fabricated. Yet, according to a July 2010 Kaiser Family poll, a year after both McCaughey’s assertion about mandatory end-of-life counseling sessions and Palin’s death panel claim on Facebook, 36% of seniors believed that the law\(^{241}\) would permit the government to make decisions about care at the end of life for Medicare recipients.\(^{242}\)

\(^{237}\) Fredthompson, Fred Thompson, Betsy McCaughey Interview, YOUTUBE (July 27, 2009), https://www.youtube.com/watch?v=89hpyOjjiGk.

\(^{238}\) See Nyhan, supra note 233, at 8.

\(^{239}\) See Palin, supra note 223.

\(^{240}\) KAISER FAMILY FOUND., KAISER HEALTH TRACKING POLL 4 (July 2010), http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-july-2010/.

\(^{241}\) By July 2010, the date of the Kaiser Family Foundation poll, the Act had been promulgated. 118 Pub. L. No. 11-1148, 124 Stat. 119 (2010).

\(^{242}\) KAISER HEALTH TRACKING POLL, supra note 240, at 5. Less than half of those polled found the claim to have been false. Id.
In fact, the provision at issue said nothing about rationing and did not require anyone—neither patients nor clinicians—ever to talk about advance care planning. It simply provided for paying physicians for time devoted to conversations with Medicare patients about advance care planning. More specifically, the provision did not mandate advance-care-planning conversations every five years. Rather, the provision limited payment for such conversations to once every five years, allowing for payment more often if the patient was diagnosed with a serious illness. In the end, the provision was deleted before Congress promulgated the PPACA. The Senate did not include the provision in its bill, passed in December 2009, and renamed it the “Patient Protection and Affordable Care Act” (the name of the act that the President signed in 2010).

The disparaged provision would only have paid clinicians for conversations about advance care planning, but could well have provided inspiration for a more general effort to encourage patient-centered care focused around communication between patients and their primary-care doctors, and, sometimes, between patients and other clinicians. Communication about advance care planning is not fundamentally distinct from other patient-clinician conversations about health and health care more generally. On this, it is instructive to compare language from the 2009 House Bill 3200 with more recent discussions of patient-centered care.

Section 1233 of the House bill described consultations in which practitioners would explain advance care planning to their patients, describe available “end-of-life services and supports,” offer “information needed for an individual or legal surrogate to make informed decisions” about advance care planning, and inform a patient about state resources relevant to effecting the “treatment wishes of that individual” should he


245 In October 2009, the House replaced H.R. 3200, which contained the advance care reimbursement provision, with House Bill 3962. See H.R. 3962, 111th Cong. (2009). The bill that passed in the Senate in December 2009—the Patient Protection and Affordable Care Act—was House Bill 3590, which, prior to amendment, was a tax credit proposal for service members. See John Cannan, A Legislative History of the Affordable Care Act, 105 LAW LIBR. J. 131, 140, 153 (2013). House Bill 3590, as passed, mostly comprised Senate Amendment 2786, which included some content from the previous bills. Id. at 153–58. That bill passed in the Senate on Dec. 23, 2009. Id. at 158. It did not include a provision to pay physicians for conversations about advance care planning.
or she be "unable to communicate those wishes." Patient-centered care has been similarly described as "revolv[ing] around the patient" in such a way that "care is generally defined by or in consultation with patients rather than by physician dependent tools or standards." In 2001, the Institute of Medicine defined "patient-centeredness" as "health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care." And a 2007 report on patient-centered care delineates its key components to include "involvement of family and friends," "sensitivity to nonmedical and spiritual dimensions of care," and "respect for patient needs and preferences."

The negative publicity that followed the death panel claim slanted the debate and conditioned large segments of the nation to oppose the proposal to pay clinicians for advance-care-planning conversations with their patients. Part of the force of anti-PPACA publicity in general and of that opposing the advance-care-planning payment proposal, in particular, stemmed from the attempt to incorporate these matters into a larger ideological platform. Thus the debate about advance-care-planning payments was conflated with the longstanding debate about abortion.

2. Death Panels and the Abortion Debate

The death panel claimants assumed, or self-consciously selected, a set of metaphors that invoked pro-life language in criticizing both Section 1233 of House Bill 3200 and then five years later, in criticizing a renewed effort—one initiated by the American Medical Association ("AMA")—to have Medicare develop billing codes for discussions between clinicians and patients about advance care planning. In the

\[\text{246 H.R. 3200 } \S 1233(a)(1).\]
\[\text{248 Inst. of Med., Envisioning the National Health Care Quality Report 7 (2001).}\]
\[\text{250 See Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 41,686 (proposed July 15, 2015); see also Support}\]
summer of 2009, North Carolina Representative Virginia Foxx (R), described a Republican bill that would have replaced the Democrats’ health care reform bills described as “pro-life because it will not put seniors in a position of being put to death by their government.” And in 2014, in response to the AMA proposal, some public voices echoed Palin’s 2009 rhetoric. In 2014, Burke Balch, then-director of the Powell Center for Medical Ethics at the National Right to Life Committee explained that the 2014 provision that proposed paying physicians for conversations about advance care planning could result in “subtle efforts to pressure some of the most vulnerable patients to surrender their right to life.”

The similarity to language used in other contexts to describe abortion’s consequences for fetuses is readily apparent. Thus, again, rhetoric about end-of-life decision making was shaped in light of claims associated with the pro-life movement. As in the context of earlier cases about care for vegetative patients (such as Terri Schiavo) in which the

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252 The Powell Center website explains that the Center “serves as NRLC’s arm in fighting to protect the vulnerable born from both direct killing and denial of lifesaving medical treatment, food and fluids.” Robert Powell Center for Medical Ethics, NAT’L RIGHT TO LIFE COMM., http://www.nrlc.org/medethics/ (last visited Jan. 22, 2016).


254 See, e.g., Press Release, Rep. Lynn Westmoreland, Westmoreland Votes to Protect Americas Unborn Children (May 18, 2015) (available at http://westmoreland.house.gov/press-releases/westmoreland-votes-to-protect-americas-unborn-children/) (quoting House of Representative Lynn Westmoreland (R.-Ga.) that “Sanctity of Life Act” would offer life to “innocent children,” and that “[t]heir lives are the most vulnerable and we must be the voice for the voiceless”); National Right to Life Mission Statement, NAT’L RIGHT TO LIFE COMM., http://www.nrlc.org/about/mission/ (last visited Jan. 24, 2016) (stating that the National Right to Life Committee is committed to “protect and defend the most fundamental right of human-kind, the right to life of every innocent human being from the beginning of life to natural death”). The organization’s mission statement continues:

National Right to Life carries out its lifesaving mission by promoting respect for the worth and dignity of every individual human being, born or unborn, including unborn children from their beginning; those newly born; persons with disabilities; older people; and other vulnerable people, especially those who cannot defend themselves.

Id.
pro-life movement presumed to equate abortion with end-of-life choices
that limit the continuing use of life-sustaining treatment, 255 those oppos­
ing payment for advance-care-planning conversations invoked pro-life
comparisons to undermine statutory and regulatory proposals to have
Medicare pay for such conversations.

3. The Irony of the “Death Panel” Claim and the Implications
of its Success

Perhaps, the most poignant—and most disturbing—aspect of
“Obamacare” opponents’ peculiar critique of the legislative effort to pay
clinicians for discussing advance care planning with patients—in effect,
a proposal to pay clinicians to talk with patients about health care mat­
ters—is that that payment proposal would have echoed and perhaps even
revivified a very positive and life-giving component of old-fashioned
medicine. 256 The notion of patient-centered care for patients with capaci­
ty depends on clinicians and patients talking with each other.

Remarkably, the death panel claimants and their compatriots dis­
paraged an element of health care reform that seems almost expressly
aimed at preserving—or more accurately, re-creating—aspects of the
doctor-patient relationship prized before the widespread “social trans­
formation” of American medicine in the second half of the twentieth
century. 257 Even more, good health care depends on conversations be­
tween clinicians and patients. The proposal to pay clinicians for conver­
sations with patients about advance care planning offers a powerful
model for the clinician-patient relationship that assumes communication

255 See supra Part IV.B.3. (detailing Schiavo’s legal story about life-sustaining care for a
woman diagnosed to have been in a persistent vegetative state). Randall Terry, founder of Op­
eration Rescue, a pro-life group, organized demonstrations outside the facility in which Terri
Schiavo resided and equated her dying with the death of a fetus. See Smith, supra note 186; And­
ed that pro-choice groups were joined, in opposing withdrawal of care for Terri Schiavo, by
disability rights groups. See Smith, supra note 186.
256 See Joshua E. Perry, A Missed Opportunity: Health Care Reform, Rhetoric, Ethics and
Economics at the End of Life, 29 MISS. C. L. REV. 409, 416 (2010) (quoting Dr. J. James Ro­
hack, President of the American Medical Association when the “death panel” claim was first
voiced, quoted, and cited in Kevin B. O’Reilly, End-of-Life Care Provision Stirs Angst in
assn.org/amednews/2009/08/24/prsaO824.htm). Dr. Rohack viewed the provision to pay phy­
sic for conversations about advance care planning as “plain, old-fashioned patient­
centered care.” Id.
is a central component of good health care.

B. Revivifying the Coverage Provision

A year before McCaughey and Palin suggested to the nation (with significant effect) that paying clinicians for consultations with patients about advance care planning was tantamount to creating "death panels," Congress had provided for one Medicare payment to clinicians to address such issues with new Medicare recipients.\(^{258}\) Efforts to implement a broader provision—one that would pay clinicians for periodic advance-care-planning conversations with patients—faced strong opposition. Yet, a proposal published by CMS in July 2015 to create two billing codes that cover advance-care planning conversations has been finalized and extends a welcome beginning.\(^{259}\) This Part reviews efforts to provide for Medicare payments for advance-care-planning conversations between 2010 and 2015 in light of the deletion of the provision from the law that became the PPACA.

1. Proposals that Failed to Receive Adequate Support

In 2010, the CMS relied on regulatory processes to propose paying clinicians for advance-care-planning conversations.\(^{260}\) Supporters of the regulation worried that publicity, revived from the 2009 fracas about "death panels," could stymie the new regulatory effort.\(^{261}\) Indeed, that happened. In December 2010, a story appeared in the New York Times describing the proposed Medicare regulation.\(^{262}\) Other media outlets soon reported on it.\(^{263}\) In early January, CMS, expressly bowing to public concern about the regulation, deleted it from the 2011 Physician Fee Schedule.\(^{264}\)

\(^{259}\) See infra Part V.B.1.
\(^{262}\) Id.
\(^{263}\) See Leonard, supra note 260, at 882–83.
Two bills, one introduced in the House and one in the Senate in 2013, would have provided payment for consultations regarding advance care planning. The House bill, "Personalize Your Care Act of 2013,"265 proposed coverage to physicians, nurse practitioners, and physician assistants for voluntary consultations about advance care planning for both Medicare and Medicaid patients.266 The bill defined "voluntary advance care planning consultation" potentially to include (subject to the specification of the Agency's Secretary):

(A) An explanation by the practitioner of advance care planning and the uses of advance directives. (B) An explanation by the practitioner of the role and responsibilities of a proxy or surrogate. (C) An explanation by the practitioner of the services and supports available under this title during chronic and serious illness, including palliative care, home care, long-term care, and hospice care. (D) An explanation by the practitioner of physician orders for life-sustaining treatment or similar orders in States where such orders or similar orders exist. (E) Facilitation by the practitioner of shared decisionmaking with the patient (or proxy or surrogate) . . . . 267

The Senate bill, "Care Planning Act of 2015,"268 provided coverage for voluntary planning services not more often than once every 12 months (unless the patient's medical situation changed less than 12 months following an advance-care-planning conversation with his or her clinician).269 The Senate bill included among its findings the assertion that the government as the "largest purchaser of health care services" in the nation must "encourage health care providers to furnish more supportive and comprehensive advanced illness care to improve the efficacy and quality of health care delivered for generations of Americans to come."270

In 2014, payment to clinicians for discussions about advance care planning was again attempted through the regulatory process.271 At that

266 Id. § 2(a)(1)(B).
267 Id.
269 Id. § 3(a)(2).
270 Id. § 2(9).
271 See Support for Medicare Coverage of End of Life Discussions Among Providers, LIFE MATTERS MEDIA (Sept. 9, 2014), http://www.lifemattersmedia.org/2014/09/support-medicare-coverage-end-life-discussions-among-providers/. Two codes were proposed, in fact. The first (99497) would have provided for payment for discussion about "advance directives such as standard forms . . . by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family members(s), and/or surrogate." The second
time, the American Medical Association ("AMA") submitted billing codes to CMS that would have paid medical providers for time spent discussing advance care planning with Medicare patients.272 The AMA proposed that Medicare pay for a 30-minute discussion about such planning with Medicare patients.273 In late 2014, CMS tabled the proposal.274 The reasons for that action remain unclear275 though CMS claims it needed more time to garner comments on reimbursements under the two codes.276

2. 2015: A New CMS Proposal and a Finalized Rule

In July 2015, CMS again relied on the regulatory process to propose two codes that would allow clinicians to bill for advance-care-planning conversations.277 A letter to Sylvia Burwell, Secretary of Health and Human Services, sent two months earlier and signed by over 60 health care organizations, including the AMA, the American Nurses Association ("ANS"), and the AARP, urged that Medicare offer the

(99498) would have provided payment for discussion that extended beyond 30 minutes. See Medicare Declines to Reimburse Physicians for End of Life Discussions in 2015, LIFE MATTERS MEDIA (Dec. 9, 2014), http://www.lifemattersmedia.org/2014/12/medicare-declines-reimburse-physicians-end-life-discussions-2015/.

272 See Support for Medicare Coverage of End of Life Discussions Among Providers, supra note 271.

273 Id.

274 Id.

275 Life Matters Media quotes Thaddeus Pope, a law professor at Hamline University, to have opined that CMS's response could have reflected "implementation issues or politics." Id. Pope further suggested that the code might be accepted and implemented by CMS by 2016. Support for Medicare Coverage of End of Life Discussions Among Providers, supra note 271.


277 The codes, suggested to HHS by the AMA, are numbered 99497 and 99498. Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 41,686 (proposed July 15, 2015) [hereinafter CY 2016 CMS Codes]. The CMS proposal describes the codes at issue:

CPT code 99497 (Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional; first 30 minutes, face-to-face with the patient, family member(s) and/or surrogate); and an add-on CPT code 99498 (Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional . . . ).

Id. at 41,773.
codes developed by the AMA. The letter explained:

Published, peer-reviewed research shows that [advance care planning (ACP)] leads to better care, higher patient and family satisfaction, fewer unwanted hospitalizations, and lower rates of caregiver distress, depression and lost productivity. ACP is particularly important for Medicare beneficiaries because many have multiple chronic illnesses, receive care at home from family and other caregivers, and their children and other family members are often involved in making medical decisions.

CMS proposed that the two codes “should be reported when the described service is reasonable and necessary for the diagnosis or treatment of illness or injury.” The proposal provided illustrations:

For example, this could occur in conjunction with the management or treatment of a patient’s current condition, such as a 68 year old male with heart failure and diabetes on multiple medications seen by his physician for the evaluation and management of these two diseases, including adjusting medications as appropriate. In addition to discussing the patient’s short-term treatment options, the patient expresses interest in discussing long-term treatment options and planning, such as the possibility of a heart transplant if his congestive heart failure worsens and advance care planning including the patient’s desire for care and treatment if he suffers a health event that adversely affects his decision-making capacity.

Thus, the proposal expressly presented the codes as providing coverage for health care thereby making it clear that clinician-patient conversations about the patients’ medical situation and proposed care are part of the practice of good health care. The proposed codes did not cover conversations held “at the beneficiary’s discretion, ... under section 1861(hhh)(2)(G) of the Act” (concerning Medicare patients’ annual wellness visit). CMS responded to comments on the proposed codes that favored providing for reimbursement for advance care planning during a patient’s annual wellness visit. That possibility was added to the codes, as finalized in November 2015. The codes thus cover consultations...

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279 Id.
281 Id.
282 Id.
283 Final Rule, Revisions to Payment Policies Under the Physician Fee Schedule and Oth-
about advance care planning in conjunction with Evaluation and Management services or as an optional component of the annual wellness visit. Medicare’s paying for these conversations will enrich the clinician-patient relationship and, correlative, promises to improve health care.

In short, the new codes serve important purposes. Most obviously, they provide for reimbursing clinicians for time given to an essential part of health care—talking with patients. Second, the CMS codes explicitly categorize such conversations, at least in a limited context, as central to health care. To the extent that that message is more widely internalized among clinicians and patients, it will more likely be accepted and even generalized by other payers.

The next Part of this Article describes a number of models for effecting advance care planning. It focuses on one model that is being developed in New York State. This model is unusual in that it depends on the integrated work of interdisciplinary teams; these teams include lawyers, clinicians, public health professionals, and social science researchers, working with the assistance of university graduate and professional students.

VI. ADVANCE CARE PLANNING: EDUCATION AND IMPLEMENTATION

Broad changes in responses to advance care planning will be furthered as the public becomes increasingly aware of the value of advance care planning and of the centrality of conversations between patients and clinicians—as well as conversations between patients and potential surrogates—to advance care planning. This Part presents several approaches developed to educate the public about advance care planning and to increase the percent of adults who have completed advance directive forms and engaged in honest conversations about their health care preferences with their clinicians and surrogate(s).

Each of the models described in this Part encourages people to complete advance care directives and to discuss health care preferences with potential surrogates and with clinicians—especially primary care providers. Further, each would seem to further the goals set by the Institute of Medicine’s 2014 report on dying in America:

For most people, death results from one or more diseases that must be

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284 Id.
managed carefully over weeks, months, or even years. Ideally, health care harmonizes with social, psychological, and spiritual support as the end of life approaches.

As much as people may want and expect to be in control of decisions about their own care throughout their lives, numerous factors can work against realizing that desire. Many people nearing the end of life are not physically or cognitively able to make their own care decisions. It is often difficult to recognize or identify when the end of life is approaching, making clinician-patient communication and advance care planning so important. Understanding that advance care planning can reduce confusion and guilt among family members forced to make decisions about care can be sufficient motivation for ill individuals to make their wishes clear.

A. Encouraging Conversations About Advance Care Planning

"Respecting Choices," a program developed in LaCrosse, Wisconsin, in the 1990s has provided a model for other programs. Bud Hammes, a medical ethicist at the Gundersen Lutheran Health System in LaCrosse, created Respecting Choices in response to a set of conundrums facing the loved ones and health care providers of very ill patients without capacity to make medical decisions for themselves. Clinicians in LaCrosse found that patients' family members were often ignorant of their loved ones' pre-incapacity health care preferences. That made medical decision making extraordinarily burdensome for patients' health care agents. In response, a cadre of clinicians, attorneys, clergy, and others working in LaCrosse joined together in order to educate the community about medical choices, especially in end-of-life situations.

Respecting Choices has been remarkably successful. In LaCrosse, by 2009, over 95% of adults had completed advance directives. That compares with about 25 to 30% of adults in the nation. The success in

285 DYING IN AMERICA, supra note 44, at S-1–S-2.


288 Id.

289 Id.

290 See Hatkoff et al., supra note 287.

291 Id.; see also DYING IN AMERICA, supra note 44, at 3–7 (noting that fewer than 30% of adults have had conversations about end-of-life care).
LaCrosse has not resulted in health care professionals rationing care to the elderly and dying people. Moreover, in LaCrosse, the average lifespan is about a year longer than the national average lifespan. Yet, patients in LaCrosse spend less time in the hospital near the end of life than do patients in other places, and the cost of hospitalization for LaCrosse’s elderly population is “unusually low.”

Atul Gawande reports that the intensive care unit (“ICU”) at the Gundersen Lutheran Hospital in LaCrosse seems to resemble many others in the nation—until one looks more carefully. When Gawande visited the Gundersen ICU, all of the patients were terribly ill, but none had a terminal condition. ICU patients in LaCrosse are far more likely to recover than to linger. The transformation in LaCrosse has depended almost entirely on a focused and committed effort to educate community members (not just old, sick people, but everyone) about advance care planning and, in that way, to encourage everyone to engage in conversations about advance care planning. In LaCrosse, “[e]veryone talks about it.”

Since Respecting Choices was created, similar programs have been developed elsewhere. The Conversation Project suggests that implementing care without talking with a patient about his or her “care wishes” or delivering care not in harmony with a patient’s expressed wishes is “on a par with medical errors.” The Conversation Project offers a “Starter Kit,” available online, to help people engage in conversations about advance care planning.
The Project’s website offers some straightforward statistics that make the need for conversations about advance care planning transparent. For instance, although the great majority of people (90%) assert that talking to loved ones about advance care planning is important, only about a quarter have actually engaged in such a conversation. Similarly, most people (82%) say that it is important to put in writing their end-of-life preferences, but very few have spoken to a clinician about it (7%). A number of other projects further this work in various parts of the country.

B. The CHAT Project

This Section focuses on a recent addition to the models created throughout the country in the wake of the success of Respecting Choices in LaCrosse, Wisconsin. Conversations: Health And Treatment (“CHAT”), developed by an interdisciplinary team of attorneys, clini-

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305 See id.
306 See id.
307 See id.
308 See, e.g., Empath Choices for Care, EMPATH HEALTH, https://www.empathchoicesforcare.org/ (last visited Jan. 27, 2016); EPEC PROJECT, EDUCATION FOR PHYSICIANS ON END-OF-LIFE CARE (EPEC) PARTICIPANT’S HANDBOOK (1999), http://www.ama-assn.org/ethic/epec/download/module_1.pdf. The Institute for Ethics at the American Medical Association created the EPEC project. Id.

Dr. Patricia Bomba has spearheaded a focus on end-of-life planning in New York State. She now leads a program (“Compassion and Support at the End of Life”). “The Community-Wide End of Life/Palliative Care Initiative” was originally co-led by Excellus BlueCross BlueShield and the Rochester Health Commission. About Us, COMPASSION & SUPPORT, https://www.compassionandsupport.org/index.php/about_us/leadership (last visited Jan. 27, 2016). The Initiative encourages health care communities to have advance directive forms, accepted by all health care institutions and clinicians providing care within the community. About Us: Core Principles and Goals, COMPASSION & SUPPORT, https://www.compassionandsupport.org/index.php/about_us/core_principles_goals (last visited Jan. 27, 2016). Further, Dr. Bomba played a crucial role in bringing the MOLST form (“Medical Orders for Life-Sustaining Treatment”) to New York State. MOLSTs are physician orders that allow patients to provide for the refusal of life-sustaining treatment. Within nursing homes and hospitals, MOLSTs can provide for any physician order about life-sustaining care. Outside of hospitals, they provide for Do Not Resuscitate (“DNR”) and Do Not Intubate (“DNI”) orders. Medical Orders for Life-Sustaining Treatment (MOLST), N.Y STATE DEPT HEALTH, http://www.health.ny.gov/professionals/patients/patient_rights/molst/ (last visited Jan. 27, 2016).

309 The CHAT project has been developed by the Gitenstein Institute for Health Law & Policy at the Maurice A. Deane School of Law at Hofstra University and the Northwell Health
cians, public health professionals, social science researchers, and university students, was developed as the result of a partnership between the Maurice A. Deane School of Law at Hofstra University and the Northwell Health, both in Nassau County, N.Y.\(^ {310}\) CHAT is unusual among programs encouraging advance care planning in that it relies on the resources of several university professional schools and departments as well as on the resources of a major health care system. The program, now operating in a few counties in southern New York State,\(^ {311}\) strives to educate communal, professional, academic, governmental, and patient groups about advance care planning; to encourage "chats" about advance care planning; to offer one-on-one assistance to people ready to complete New York State’s advance-care-planning forms; to encourage people to reexamine and, if appropriate, re-draft advance-care-planning documents over time; and to identify and remedy gaps in state laws that pertain to advance care planning.\(^ {312}\) CHAT responds to the concerns of a heterogeneous population.\(^ {313}\) Reviewing a few of CHAT’s legal, clinical, and communal foci provides a broad overview of the effort to make advance care planning a routine and comfortable process in a community with many ethnic, religious, and language groups and a steep socioeconomic hierarchy.\(^ {314}\)

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\(^{310}\) See id.

\(^{311}\) CHAT participants are now working in geographic areas surrounding Hofstra University and the North Shore-LIJ Health System.


\(^{313}\) The county’s population in 2014 was about 1,358,000. In 2013, the population included African Americans (12.6%), American Indians or Alaska Natives (0.5%), Asian (9.1%), Native Hawaiian and Other Pacific Island (0.1%), Two or More Races (1.7%), Hispanic or Latino (16.1%), and White (62.3%). Over one-fifth of the population was foreign born (1990–2013). The median household income (2009–2013) was high—$97,690. Yet, 6% of the population lived below the federal poverty level. State and County Quick Facts, Nassau County, New York, U.S. CENSUS BUREAU, http://quickfacts.census.gov/qfd/states/36/36059.html (last visited July 6, 2015).

\(^{314}\) This Section focuses on the development and parameters of the CHAT project. It also, however, refers to other programs, some of which have provided models for CHAT, and it
I. The Law and Advance Care Planning

CHAT's work reflects the multi-dimensional parameters of advance care planning. CHAT participants engage in education, advocacy, individual consultations, and research. The legal arm of CHAT offers education about advance-care-planning laws, conducts research aimed at identifying laws most likely to serve the needs of patients, their loved ones and their clinicians, and advocates for change once gaps in the law have been identified. Law students, supervised by attorneys, offer one-on-one consultations with anyone desirous of such guidance. New York state laws govern these consultations.

A brief review, noting highlights only of New York's advance-care-planning laws, suggests the broad outlines of most states' responses to medical decision making for patients without capacity. (Details vary from state to state.) New York is unusual among the states in requiring physicians to "offer" to provide terminally ill patients with "information and counseling regarding palliative care and end-of-life options appropriate to the patient." N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2015). California has a similar right-to-know law. CAL. HEALTH & SAFETY CODE § 442.5 (West 2015). See also Katherine B. Ledden, Comment, A Nudge in the Right Direction with a Stick the Size of CMS: Physician-Patient Communication at the End of Life, 6 ST. LOUIS U. J. HEALTH L. & POL’Y 389, 412-17 (2013) (considering New York and California "right to know" laws).

In 1990, New York passed the Health Care Proxy Act. CHAT operates in New York. Thus, New York advance-care-planning laws are central to CHAT's work.

The provision presumes all adults to be competent for this purpose unless they have been "adjudged incompetent or otherwise adjudged not competent to appoint a health care agent" or have been subject to the appointment of a committee or guardian of the person pursuant to Article 78 of the state's mental hygiene law or Article 17-A of the surrogate's court procedure act. Pub. Health Law § 2981(1).

State law directs that the form be signed, dated, and witnessed by two adults who also must sign the document. Notarization is not necessary. Id. § 2981(2). The statute further provides:

(a) The health care proxy shall: (i) identify the principal and agent; and (ii) indicate that the principal intends the agent to have authority to make health care decisions on the principal's behalf, (b) The health care proxy may include the principal's wishes or instructions about health care decisions, and limitations upon the agent's
(86%, by one estimate) of medical decisions about the withholding or withdrawal of life-sustaining care is made by surrogates, not by the patient. The burden on surrogates can be terrible. Studies have correlated the "surrogate experience" with "the surrogate's level of confidence in his or her knowledge of which treatment the patient would have wanted." Among significant stressors that make the surrogate's role more difficult, several—such as "uncertainty of patient's preferences" and "conflict with clinicians and family"—can be mitigated by advance care planning that includes honest conversations with potential surrogates and with the patient's clinicians. All CHAT participants direct anyone ready to complete advance directive forms to examine and understand the forms and then wait to complete them until one has engaged in conversations with one's potential surrogates and one's clinicians.

So-called living wills are not expressly provided for by New York's law, but they can be drafted as supplements to instructions for one's agent that are provided on the proxy form or in lieu of express instructions on the form itself. Many New York lawyers advise their use.
Living wills are sometimes preferred to including relevant instructions on the proxy form because a living will can be re-drafted over time without the need to complete a new, witnessed proxy form. Living wills, however, if not composed with care, can limit an agent’s discretion by providing the agent with instructions that, in the nature of the case, were not composed in light of the patient’s actual medical situation at the time that medical decision making becomes necessary or of medical options when health care decisions are actually needed. On the whole, health care agents, and the patients for whom they make decisions, will be better served by having engaged in conversations about the principal’s health care preferences and choices than by a detailed written document that may stymie the agent’s decision-making authority in a manner that the principal, if capable, would not want. Attorneys, clinicians, or others helping patients complete proxy forms, should be aware of and able to recommend some of the programs that guide people through such conversations comfortably.

Those counseling clients about advance care planning in New York should address some limits of the law with clients. First, anyone who has completed a proxy form should be urged to re-examine it over time. An individual’s preferences may change as his or her health status changes, and the principal may want to re-consider the agent named on the form. An agent may die or move away or simply lose contact with the principal. Further, a proxy form is of little use if it cannot be located when needed. At a minimum, copies of the form should be given to the proxy, any alternate proxy, and the principal’s primary care clinician.

Should a person fail to complete a health proxy form in New York and thus not name a proxy decision maker, a surrogate decision maker is

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326 Id.
327 Id. Engaging in such conversations further ensures that the agent identified on a proxy form will not learn of his or her appointment only after the principle has lost capacity and is in need of medical decision making. New York law does not require the agent to sign or even read the principal’s health care proxy form. This can obviously lead to confusion and significant discomfort for the agent if he or she is unaware of the appointment before his or her services are needed.

identified pursuant to the Family Health Care Decisions Act.\textsuperscript{329} This law has been important to health care facilities and family members, but the act's prescriptions may not reflect the pre-incompetency preferences of a particular patient. The surrogate decision maker chosen pursuant to the priority assigned by the law may not be someone whom the principal would have wanted to make important decisions for him or her.\textsuperscript{330} Moreover, a patient without a completed health care proxy form is probably less likely than those with advance directives to have engaged in open and honest conversation with potential surrogates about his or her preferences.

CHAT’s advocacy arm has identified several gaps in federal and state law. First, all insurers should pay clinicians for time devoted to conversations with patients about advance care planning.\textsuperscript{331} Further, advance-care-planning laws should require primary care clinicians to offer to discuss advance care planning with each patient whenever that patient has a change in his or her health situation or a change that suggests a need to identify a new surrogate, as well as periodically (e.g., every five years). Moreover, in order to ensure the availability of a person’s advance-care-planning document when it is needed, clinicians should use electronic health records that facilitate inclusion of these documents. The generalization of these improvements depends on legislative activity and education for clinicians about the significance of advance care planning. Each of these developments can best be accomplished through interdisciplinary teams, such as those developed within CHAT. Such teams allow attorneys to share their expertise about state law with clinicians, public health professionals, social workers, clergy, and others.\textsuperscript{332}

\textsuperscript{329} N.Y. PUB. HEALTH LAW § 2994-a et seq. (McKinney 2015).

\textsuperscript{330} In order of priority, New York law identifies as the decision maker for a patient without capacity, who did not complete an advance directive: 1. a guardian appointed pursuant to the mental hygiene law, a spouse, if not legally separated from the patient, or the patient’s domestic partner; 3. an adult child; 4. a parent; 5. an adult sibling; 6. a close friend. Id. § 2994-d.

\textsuperscript{331} See supra Part V. The CY 2016 Medicare reimbursement rule makes a start, but state and federal lawmakers should go further and require insurers to provide coverage for optional advance care planning in the event of a change in health status as well as periodically.

\textsuperscript{332} Although beyond the scope of this Article, it is important to note that CHAT provides opportunities for students in a variety of professional programs, working on interdisciplinary teams, to benefit by sharing experiences and knowledge with students and professionals in other disciplines.
2. Clinicians and Advance Care Planning

CHAT’s clinical participants work within a health care system committed to helping patients and patients’ surrogates understand medical options and advance care planning and to programs that guide clinicians in how best to do this. The Institute for Healthcare Improvement (“IHI”) delineates five “core principles” that can direct health care institutions to guide patients through conversations about end-of-life care; safeguard information discerned during those conversations; and then respect patients’ preferences “at the appropriate time.”

IHI’s core principles harmonize with CHAT’s goals. The first principle recognizes the importance of guiding patients and their families (hopefully long before the end of life) to consider “what matters most to them about care at the end of life.” IHI’s second core principal—serving as a steward for information about patients’ preferences—is described to be as fundamental as “knowing, confirming, and documenting [a patient’s] allergies.”

The third principle focuses on the significance of constructing “a patient centered plan of care” and on a commitment to implementing that plan (or a transformation of it if patient preferences change over time). The fourth IHI principle advises clinicians to complement their guidance to patients in advance care planning by themselves engaging in advance care planning.

This raises some interesting questions about clinicians own preferences for end-of-life care. Those preferences, at least in the abstract, do not seem to differ dramatically from those of the nation’s majority. Physicians, unlike many non-physicians, however, almost all actually do refuse aggressive care when diagnosed with a terminal illness.

In 2011, Ken Murray, a California family practice physician, authored a short piece entitled How Doctors Die that went viral quickly. Doctors, Murray noted, have access to health care and know the

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333 See supra note 309–310 and accompanying text (listing CHAT partners).
334 Id. at 4.
335 Id. at 12.
336 Id.
337 McCUTCHEON ADAMS ET AL., supra note 303, at 13.
338 Id.
340 Murray, supra note 53.
341 O’Neill, supra note 339.
medical options. They do not “want to die; they want to live.” Yet, they do not die “like the rest of us.”

Murray writes:

[T]hey know enough about death to know what all people fear most: dying in pain, and dying alone. They’ve talked about this with their families. They want to be sure, when the time comes, that no heroic measures will happen—that they will never experience, during their last moments on earth someone breaking their ribs in an attempt to resuscitate them with CPR (that’s what happens if CPR is done right).

Murray’s commentary strongly supports training clinicians that it is acceptable to treat patients as they, themselves, would want to be treated.

Finally, the fifth IHI principle recommends attention to culturally sensitive connections with patients:

Providers can fall short of their aim of providing patient-centered end-of-life care if they do not account for cultural influences—religious, ethnic, socioeconomic, educational, and geographic—that impact how a patient approaches end-of-life care. This area of work is vital for becoming Conversation Ready.

These concerns suggest the need to develop training programs in advance care planning for staff at health care facilities. The Institute of Medicine report titled Dying in America reports that too often physi-
C. **Implications for the Cost of Good Health Care?**

Accusations such as Palin’s “death panel” claim in 2009\(^{351}\) based on the presumption that advance care planning serves to ration care for

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\(^{348}\) _DYING IN AMERICA_, supra note 44, at 16 (citation omitted).

\(^{349}\) GAWANDE, _supra_ note 295, at 178.

\(^{350}\) Much of this work has been undertaken by students in Hofstra’s Master of Public Health program. In this work, they are supervised and directed by University professors in public health and law and by clinicians and researchers at Northwell Health (previously known as the Northshore-LIJ Health System). _See supra_ note 309–310 and accompanying text (describing composition of CHAT program’s representatives).

\(^{351}\) _See supra_ notes 233–235 and accompanying text.
the sake of cost savings—are bogus. Some commentators have argued that effective advance care planning is likely to encourage people near the end of life to consider palliative care and hospice care sooner than they otherwise might. Even if that is so—and advance care planning aims to further patients’ preferences, not to stymie them—it is a mistake blithely to assume that palliative and hospice care decrease end-of-life costs. But quite as important, hospice care at the end of life does sometimes lengthen patients’ lifespans.

There is still no unanimity of opinion among researchers or policy advocates about the consequences of advance care planning for the nation’s health care costs. In LaCrosse, advance-care-planning conversations between clinicians and patients are routine and expensive. Hospitals in LaCrosse, however, also spend far less in the last two years of patients’ lives than does any other place in the nation.

The Institute of Medicine’s 2014 report on dying in the U.S. notes that “[i]n the absence of adequate documented advance care planning, the default decision is to treat a disease or condition, no matter how hopeless or painful.” The report then suggests that “[b]ecause most people who participate in effective advance care planning choose maximizing independence and quality of life over living longer, advance care planning can potentially save health care costs associated with unnecessary and unwanted interventions.”

It may be that advance care planning will result in lower health care costs. Some researchers, however, have suggested that it may increase costs. One study of fee-for-service Medicare recipients residing in nurs-

352 See Amol K. Narang et al., Trends in Advance Care Planning in Patients with Cancer: Results from a National Longitudinal Survey, 1 JAMA ONCOLOGY 601, 602–07 (2015) (finding completion of durable powers of attorney did not necessarily correlate with end-of-life decisions about care, in large part because of the absence of serious conversations between patients and clinicians and surrogates and clinicians; in short, the default position, absent informative discussions, is to treat aggressively).

353 Charles F. Von Gunten et al., Why Oncologists Should Refer Patients Earlier for Hospice Care, CANCER NETWORK (Nov. 30, 2011), http://www.cancernetwork.com/end-of-life-care/why-oncologists-should-refer-patients-earlier-hospice-care ("[H]ospice care does not shorten life expectancy. For certain diagnoses, hospice enrollment is actually associated with longer survival times.").

354 See Shapiro, supra note 289 (reporting that advance care planning conversations cost the hospital system "millions of dollars a year").

355 Id. Shapiro reports that according to the Dartmouth Atlas of Health Care, the average cost for care during the last two years of life at the Gundersen Healthcare Network in LaCrosse is approximately $18,090. In the nation, the average is approximately $26,000. Id.

356 DYING IN AMERICA, supra note 44, at S-9.

357 Id.
ing homes in 2004 and 2009 found an increase in costs among those in hospice care at the end of life. Nursing home decedents not electing hospice in 2009 saw a mean increase in expenditures of $3,143, as compared with a $9,906 increase among those electing hospice in 2009 (defining increases “relative to their matched 2004 non-hospice users, for a net adjusted increase of $6,761”). Some part of the increase might have been a consequence of Medicare’s payment design.

The landscape of hospice providers in the United States had changed, from small not-for-profit providers to increasingly for-profit hospice chains. The percent of persons receiving hospice care in a nursing home tripled from 14% of Medicare decedents in 1999 to nearly 40% in 2009. Medicare pays a per-diem rate for routine hospice care, regardless of whether services are provided, which raises the policy concern that profit motives may be driving selective enrollment of nursing home residents without cancer, who have longer hospice lengths of stay.

Whether or not hospice participation increases costs, there is powerful “evidence that hospice improves the quality of care.” Similarly, whether advance care planning proves ultimately to decrease or to increase the nation’s health care budget, it improves health care and serves clinicians, patients, and patients’ loved ones.

VII. CONCLUSION

By the early nineteenth century, modernity had ushered in an age that was displacing religions’ role in defining and monitoring society’s most fundamental values and beliefs with secular truths, often identified by science, analyzed by philosophy and its cousin disciplines among the humanities, and regulated by a civil polity increasingly committed to autonomous individuality and dependent on the presumption of consensus rule making. Those changes reset the social axis in terms of which people understood themselves and their world. The consequences were revolutionary.

Almost inevitably new visions of death emerged—or more accurately, new options for dying largely encompassed visions of death.

358 Pedro Gozalo et al., Changes in Medicare Costs with the Growth of Hospice Care in Nursing Homes, 372 N. ENGL. J. MED. 1823, 1823 (May 7, 2015).
359 Id. at 1828.
360 Id. at 1830.
361 Id. at 1829 (footnotes omitted).
362 Gozalo et al., supra note 358, at 1830.
These changes were evident even before technological developments facilitated understandings of dying as a process that could ward off death for long periods.\textsuperscript{363} Almost no one expressly refuted the inevitability of death—at least not until recently.\textsuperscript{364} But beginning in the middle decades of the twentieth century, advances in medicine and technology made it possible to hold death at bay with life-sustaining treatments for months or even years.\textsuperscript{365}

Over time it became clear to many, including the clinicians and loved ones of dying patients that far less was being gained than had once been imagined by the prolongation of the dying process. Yet, requests to withhold or withdraw life-sustaining care were met with resistance in cases in which those requests were made by surrogates for terminal and permanently vegetative patients without capacity. State legislatures responded by providing for advance directives that facilitated the appointment of a surrogate and provided for the delineation of medical preferences by capable adults contemplating the need for medical decisions complicated by the loss of capacity.\textsuperscript{366}

Yet, legal provision for advance care planning has not adequately encouraged people to engage in the process. Almost all (about 90\%) of Americans say they hope to die at home.\textsuperscript{367} Yet, only about one-third of Medicare recipients (65 and older) do die at home.\textsuperscript{368} Many people never complete advance directives.\textsuperscript{369} Furthermore, successful advance care planning—planning that serves the once-competent patient as well as his or her surrogates and clinicians—depends both on completion of ad-

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\textsuperscript{363} See \textit{supra} notes 29–33 and accompanying text.


\textsuperscript{365} See \textit{supra} Part III.B.

\textsuperscript{366} See \textit{supra} Part IV.B.


\textsuperscript{368} \textit{Id.}

\textsuperscript{369} \textit{Id.} African-Americans and Hispanics complete advance directives less often than whites; those in lower-income groups and with less education also complete advance directives less often than people with more money and/or more education. \textit{Id.}
vance directives and on honest conversations—sometimes more than a few conversations—370—with potential surrogates and clinicians.

Changes in federal and state law can facilitate this. Insurers, including government insurers, should cover periodic and episodic advance-care-planning conversations between clinicians and patients for all adults.371 Additionally, state laws should require clinicians to offer to engage in conversations with patients about advance care planning. The conversations should not be mandatory, but clinicians should be encouraged to suggest to patients the usefulness of such conversations at least once every five years (and more frequently if a patient’s health status changes). Further, all adults should be encouraged (by lawyers, clinicians, and public health experts) to engage in serious conversations about medical preferences with potential surrogates and with their primary care clinician as well as others involved in their health care. Excellent models for beginning and carrying out these conversations are available.372

Dying should not be prolonged simply because it can be. This is ever the more compelling for patients who may be in pain, even though not capable of entertaining their own medical decisions. Patients who, while capable, would have chosen to discontinue life-sustaining care should have that choice made for them after they lose capacity to make it for themselves. And surrogates and clinicians, working together, should have the solace of knowing, and the authority to act in accord with, the pre-incompetency medical wishes of the patients for whom they are making decisions—whether those wishes suggest that care should be discontinued or that specific sorts of care should be provided.

Interdisciplinary efforts to review, improve, and develop advance-care-planning tools will encourage improvements in existing laws, support clinicians who are ready to engage in advance-care-planning conversations with their patients, and encourage everyone to “CHAT” with his or her clinicians and with potential surrogate decision makers. These developments are extraordinarily important in and of themselves. They also provide models of good health care.

370 Some patients need to engage in repeated conversations with clinicians about advance care planning before they understand the issues and can knowledgably offer personal responses. See 10 FAQs, supra note 367.
371 These conversations should be covered for older, sick children as well. The complexities of pediatric decision making, even for older adolescents, however, are beyond the scope of this Article.
372 See supra Part VI.