WHO HAS A WILL TO LIVE?: WHY STATE REQUIREMENTS FOR ADVANCE DIRECTIVES SHOULD BE UNIFORM(LY REVISED)

INTRODUCTION

In 2002, the U.S. Department of Health and Human Services's Centers for Medicare and Medicaid Services ("CMS") published a booklet titled *Own Your Future*.¹ The title is telling as it reflects not only its content and CMS's attempt to help the elderly plan for their futures, but also a fundamental value of American society.² Americans want to be autonomous and exercise control over their futures.³ This value permeates every area of American life, including decisions about health care.

Specifically, end-of-life care often presents the most critical of these medical decisions. To aid in making challenging end-of-life care decisions, advance directives offer individuals a concrete method for ensuring that end-of-life care agrees with their wishes. Yet, the majority of Americans have not taken advantage of advance directives and the opportunity to own their futures.⁴ This is the unfortunate reality despite federal and state advance directive legislation that has been in place since the early 1990s, despite an ever-aging population, despite imminent shortages in the supply of health care, and despite changes in the administration of the United States healthcare system.

Although advance directives are by no means a total cure for the difficult end-of-life discussions that families inevitably must face in the emergency room,⁵ advance directives can provide a means by which patients may effectively protect their interests. This Note challenges

 $^{^1}$ CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP'T OF HEALTH & HUMAN SERVS., PUB. NO. 05-E004-1, OWN YOUR FUTURE (2002).

 $^{^2~}$ Id. at 7 (encouraging Americans to take their futures into their own hands by making long-term health decisions ahead of time).

³ In the words of the Supreme Court, "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." Union Pac. Ry. v. Botsford, 141 U.S. 250, 251 (1891).

⁴ ASSISTANT SEC'Y FOR PLANNING & EVALUATION, U.S. DEP'T OF HEALTH & HUMAN SERVS., ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS 13 (2008) [hereinafter 2008 REPORT TO CONGRESS] (reporting that only a small percentage of American adults have completed advance care planning and advance directives).

⁵ While advanced planning does not necessarily improve patient outcomes, it at least serves the important objective of improving communication between patients and family members. *See* K. LORENZ ET AL., AGENCY FOR HEALTHCARE RESEARCH & QUALITY, END-OF-LIFE CARE AND OUTCOMES: SUMMARY 5 (2004). The foundational question, however, is whether the patient's interests are protected.

states to act *now* to develop legislation that will encourage their residents to own their healthcare futures. While working together on a national level, states should create and implement uniform requirements and a national registry for advance directives.

This Note argues that states should do three things. First, states should reevaluate existing legislation for advance directives. Second, they should adopt uniform standards for durable powers of attorney, living wills, dispute resolution, and registration that apply to healthcare providers. Finally, states should include the disabled and elderly population in the legislative process.

Part I of this Note provides a survey of contrasting views on advance directives, a comparison of state advance directive legislation, and an overview of previous efforts to achieve uniformity among state advance directive laws. Part II discusses, first, how changes in population and in the national healthcare system may affect advance directives and end-of-life treatment, and second, how the inefficiencies of the status quo create problems with enforcing and honoring advance directives. Part III argues that a uniform approach to advance directives should be addressed on a state level. Part IV considers possible models for a uniform advance directive law. Finally, Part V summarizes why states must act now to reform advance directive legislation.

I. HISTORY AND CURRENT USAGE OF ADVANCE DIRECTIVES

Grounded in the principle of patient autonomy, an "advance directive" is an individual's written expression of his wishes for health care if he becomes incapacitated.⁶ Advance directives also give patients a means to have those wishes protected and respected.⁷ An advance directive may include a living will, a durable power of attorney for health care, or both.⁸ An advance directive may also include specific instructions for medical procedures, including artificial nutrition and hydration ("ANH"), general life-sustaining treatment, do not resuscitate orders ("DNR"), or even the use of particular antibiotics.⁹ Advance directives also commonly include guidelines for medical care in the event of a

 $^{^6~42}$ U.S.C. § 1395cc(f)(3) (2006); see also Barbara L. Kass-Bartelmes & Ronda Hughes, Advance Care Planning: Preferences for Care at the End of Life, RES. IN ACTION, Mar. 2003, at 2.

⁷ 2008 REPORT TO CONGRESS, *supra* note 4, at 1.

⁸ 42 U.S.C. § 1395cc(f)(3); see also Gail Gunter-Hunt et al., A Comparison of State Advance Directive Documents, 42 GERONTOLOGIST 51, 51 (2002). The durable power of attorney is a document that a patient may use to designate a surrogate or proxy to make medical care decisions on the patient's behalf. Kass-Bartelmes & Hughes, *supra* note 6, at 2.

⁹ AM. HOSP. ASS'N, PUT IT IN WRITING: QUESTIONS AND ANSWERS ON ADVANCE DIRECTIVES 2–9 (rev. 2005); Gunter-Hunt et al., *supra* note 8, at 54.

persistent vegetative state ("PVS"), terminal illness, or commitment to a long-term care facility.¹⁰

As discussed in-depth in Part II, existing state laws vary in what must and may be included in advance directive documents.¹¹ The decision making standard for proxies also varies. While the "substituted judgment" standard attempts to adopt the patient's "subjective views," including his personal beliefs and values when he was well, the "best interest" standard is based on the best medical treatment or option available.¹² The Uniform Health Care Decisions Act ("UHCDA") and state laws modeled after the UHCDA apply a combination of both of these standards.¹³

Developed largely in response to litigation surrounding the so-called "right to die,"¹⁴ the Patient Self Determination Act ("PSDA") requires that healthcare providers in every state respect patients' wishes regarding their end-of-life care.¹⁵ Under the PSDA, states retain the discretion to determine advance directive provisions and the specific requirements for them to be effective.¹⁶ The PSDA also mandates that Medicare and Medicaid providers ask patients upon admission whether they already have an advance directive and offer information about how

¹³ UNIF. HEALTH-CARE DECISIONS ACT prefatory note (Proposed Official Draft 1993) ("A health-care provider or institution must comply with an instruction of the patient and with a reasonable interpretation of that instruction or other health-care decision made by a person then authorized to make health-care decisions for the patient.... A health-care provider or institution may decline to honor an instruction or decision for reasons of conscience or if the instruction or decision requires the provision of medically ineffective care or care contrary to applicable health-care standards.") (reflecting both the "subjective judgment" and "best interest" standards in the proposed model legislation's prefatory note). In adopting the UHCDA, Maine also explicitly recognized the subjective judgment and best interest standards in the prefatory note to its state legislation: "The intent and philosophy of the Act is to recognize the authority of the patient and the patient's designated agent, surrogates, or guardians to make health-care decisions based on the patient's directions and values or, if unknown, on the patient's best interest without the necessity of seeking court approval." ME. REV. STAT. ANN. tit. 18–A, §§ 5-801 to 5-817 prefatory note (1998).

¹⁴ See, e.g., Cruzan v. Dir., Missouri Dep't of Health, 497 U.S. 261 (1990); In re Jobes, 529 A.2d 434 (N.J. 1987); In re Storar, 420 N.E.2d 64 (N.Y. 1981); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E. 2d 417 (Mass. 1977); In re Quinlan, 355 A.2d 647 (N.J. 1976).

¹⁵ See Patient Self-Determination Act, Pub. L. No. 101-508, § 4206, 104 Stat. 1388-115 to -116 (codified at 42 U.S.C. § 1395cc(f) (2006)).

¹⁶ Id. § 1395cc(f)(3).

¹⁰ Gunter-Hunt et al., *supra* note 8, at 54.

¹¹ See discussion infra Part II.

¹² ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING 112, 122–23 (1989); see also Andrew Trew, Regulating Life and Death: The Modification and Commodification of Nature, 29 U. TOL. L. REV. 271, 288– 89 (1998).

to establish one.¹⁷ In addition, all Medicare and Medicaid providers must provide staff training and public education about advance directives.¹⁸ Finally, the PSDA prohibits healthcare providers from discriminating against patients who have an advance directive.¹⁹

While all states have adopted advance directive legislation, they vary in form, requirements, and even in what provisions the state must honor.²⁰ To add further complication, states have developed and codified their own protocols for determining the default healthcare decision proxy in the absence of an advance directive.²¹ While there are a substantial number of differences among states' laws,²² the low rate of adoption of advance directives is a *nationwide* problem.²³ In fact, despite federal and state laws that have been in place for nearly two decades, only eighteen to thirty-six percent of American adults actually have an advance directive, according to statistics by the U.S. Department of Health and Human Services.²⁴ Such a low rate of adoption reflects patients' unwillingness to put their final decisions regarding end-of-life care into writing.²⁵ As explained in further detail below, this unwillingness may also result from extreme views regarding the power and purpose of advance directives.

A. Diverging Views on the Purpose and Utility of Advance Directives

Polarized views on the purpose and utility of advance directives suggest that they are both misunderstood and misused. While some groups promote advance directives as a tool to ensure a less painful, less

 $^{21}\,$ Alan Meisel & Kathy L. Cerminara, The Right to Die: The Law of End-of-Life Decisionmaking § 8.01 (3d ed. Supp. 2006).

¹⁷ *Id.* § 1395cc(f)(1)(A)–(B).

¹⁸ *Id.* § 1395cc(f)(1)(E).

¹⁹ Id. § 1395cc(f)(1)(C).

 $^{^{20}}$ Gunter-Hunt et al., *supra* note 8, at 52.

²² See infra Table 1.

²³ In 2003, the Agency for Health Research and Quality reported that "[1]ess than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record." Kass-Bartelmes & Hughes, *supra* note 6, at 2. More recent statistics confirm the same troubling figures. *See* ADRIENNE L. JONES ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., PUB. NO. 2011-1209, USE OF ADVANCE DIRECTIVES IN LONG-TERM CARE POPULATIONS 1 (2011); KIRSTEN J. COLELLO ET AL., CONG. RESEARCH SERV., R40235, END-OF-LIFE CARE: SERVICES, COSTS, ETHICS, AND QUALITY OF CARE 17–18 (2009).

²⁴ 2008 REPORT TO CONGRESS, *supra* note 4, at 13.

²⁵ Helena Temkin-Greener et al., Advance Care Planning in a Frail Older Population: Patient Versus Program Influences, 27 RES. ON AGING 659, 684 (2005) ("[A]lthough participants may be comfortable and willing to discuss advance directives, they are often unwilling to put their wishes in writing, even if they understand that they may change these directives at any time. 'Many people will not sign ADS [advance directives] because it's too concrete, it's like increasing the likelihood [that they will come true], but they're willing to discuss their wishes."').

expensive, and less burdensome death ("dying well"),²⁶ other groups caution that advance directives are often ignored and may even be abused to withhold lifesaving treatment.²⁷ For example, Derek Humphry, founder of the National Hemlock Society and President of the Euthanasia Research and Guidance Organization, encourages individuals who want to end their life to use an advance directive as a litmus test in shopping for doctors who support passive euthanasia.²⁸ In contrast, organizations like National Right to Life ("NRL") caution individuals against adopting living wills and against trusting that physicians will honor their wishes.²⁹ NRL argues that instead of protecting patient autonomy, healthcare providers can use advance directives to withhold end-of-life treatment against a patient's wishes.³⁰

The American public also seems reluctant to have such advance directive documents in place, perhaps fearing that a living will may wrongfully be used as an excuse to withhold life-saving treatment.³¹ Certain communities seem especially reluctant to adopt advance directives. For example, the disabled community is sensitive to how advance directives are constructed and the treatments they contain.³²

²⁸ DEREK HUMPHRY, FINAL EXIT: THE PRACTICALITIES OF SELF-DELIVERANCE AND ASSISTED SUICIDE FOR THE DYING 10 (Delta 3d ed. 2010) (1991) ("The perfect opening gambit to test views on passive euthanasia... is to arrive at the doctor's office with your completed Living Will and Durable Power of Attorney for Health Care. Present these documents and candidly ask if they will be respected when the time comes for you to die.").

³¹ Charlotte F. Allen, *Back Off! I'm Not Dead Yet. I Don't Want a Living Will. Why Should I?*, WASH. POST, Oct. 14, 2007, at B4 ("So I say: Go ahead and sign a living will if you want. Have your doctor pull out your feeding tube or inject you with cyanide or do whatever fulfills your idea of death with dignity. But count me out. I don't want to 'die well'; I just want to die in peace.").

 32 2008 REPORT TO CONGRESS, *supra* note 4, at 21 ("If the 'voice' of the disability community was stronger in the initial development of advance directives, the focus would not be about treatments and modalities and treatment choices, but about what do people

²⁶ See, e.g., AM. HOSP. ASS'N, supra note 9, at 1.

²⁷ ROBERT POWELL CTR. FOR MED. ETHICS, NAT'L RIGHT TO LIFE, WILL YOUR ADVANCE DIRECTIVE BE FOLLOWED? 3 (rev. ed. 2011) ("Increasingly, however, doctors and hospitals, often working through ethics committees, are asserting the authority to deny life-preserving measures against the will of patients and families – and implementing that authority in a growing number of cases."), *available at* http://www.nrlc.org/ euthanasia/AdvancedDirectives/WillYourAdvanceDirectiveBeFollowed.pdf.

²⁹ WILL YOUR ADVANCE DIRECTIVE BE FOLLOWED?, *supra* note 27, at 1, 3.

³⁰ Id. at 3; see also Why the Need for a "Will to Live"?, NAT'L RIGHT TO LIFE, http://www.nrlc.org/euthanasia/willtolive/Whyneedwtl.html (last visited Nov. 27, 2011) ("Just as pro-life groups predicted, the adoption of living will legislation helped achieve a sea change in public opinion--and in the practices of the medical profession. We now see open advocacy - and implementation - of both direct killing and *involuntary* denial of lifesaving treatment against the express desires of the patient. Especially among health care providers, but also among many in the general public, the 'quality of life' ethic has largely replaced the 'equality of life' one.").

Also notably, African Americans are only one-third as likely as whites to have a living will.³³ This reluctance to adopt an advance directive may simply result from a natural fear of talking about dying,³⁴ or from a desire to let someone else make the decision.³⁵ Advance directives are often fundamentally misunderstood as documents that ensure a certain type of *death* instead of documents that ensure a certain type of *life*. When properly understood and implemented, advance directives may be a sound way for end-of-life patients to guarantee that desired treatments are not withheld and to control who makes decisions for them—not just to limit "aggressive medical care" near death.³⁶

B. Survey of State Approaches to Advance Directive Legislation

Not only do the American people differ in their understandings of the fundamental nature and purpose of advance directives, but states also vary in their approaches to regulating advance directives. Two decades after the passage of the PSDA, state statutes regulating advance directives still vary tremendously in provision and scope. For instance, while some states combine a living will and durable power of attorney for health care, others provide for only one or the other, or separate them into two documents.³⁷ Some states' advance directive forms do not even address admission to long-term care facilities.³⁸

A brief comparison of just Virginia, Missouri, and Oregon laws on advance directives illuminates several notable differences.³⁹ Virginia recognizes a patient's oral advance statement if made in the presence of an attending physician and two witnesses,⁴⁰ but Missouri requires that a living will be in writing, signed, and dated in the presence of two witnesses (unless the document is wholly in the person's handwriting).⁴¹ Likewise, Oregon requires that an advance directive be in writing and executed in the presence of witnesses.⁴²

- ³⁹ See infra Table 1.
- ⁴⁰ VA. CODE ANN. § 54.1-2983 (2009 & Supp. 2011).
- ⁴¹ MO. ANN. STAT. § 459.015 (2007 & Supp. 2011).
- ⁴² OR. REV. STAT. ANN. § 127.515 (West 2003 & Supp. 2011).

want in their lives as they are dying. What are their values and goals? What capacities do they want to maintain?").

³³ JONES ET AL., *supra* note 23, at 4; *see also* Allen, *supra* note 31, at B4.

³⁴ See Temkin-Greener et al., supra note 25, at 684.

³⁵ See 2008 REPORT TO CONGRESS, supra note 4, at 25–26.

³⁶ COLELLO ET AL., *supra* note 23, at 14, 24. At least one longitudinal study found that "less aggressive medical care and earlier hospice referrals were associated with better patient quality of life near death." *Id.* at 24.

³⁷ Gunter-Hunt et al., *supra* note 8, at 54–55.

 $^{^{38}}$ Id. at 56.

State laws are also inconsistent in terms of who may serve as a proxy for a patient and what decisions a proxy may make on behalf of a patient. Virginia limits the power of proxies by not permitting them to make decisions regarding admission to mental health facilities, psychosurgery, sterilization, abortion, and visitation.⁴³ However, Virginia does give proxies the power to make certain decisions contrary to a patient's express wishes as outlined in the code.⁴⁴ In Missouri, a physician or healthcare facility employee may act as a proxy for a family member or for a patient who is from the same religious community.⁴⁵ while in Oregon a doctor or healthcare facility employee may only serve as a

The registry of advance directives has also created a divergence among states. Although Virginia has established by statute an online registry for advance directives for health care,⁴⁷ Missouri has no such registry for streamlining advance directives.⁴⁸ Thus, a patient who registered an advance directive in Virginia cannot be guaranteed that his directive will be discovered or enforced if he is hospitalized while in another state, such as Missouri.

In addition, even though Virginia and Missouri have somewhat similar definitions of treatments that prolong life, they differ in several respects. Missouri defines a "death-prolonging procedure" using a situational definition that includes an attending physician's subjective determination that "death will occur within a short time," with or without intervention.⁴⁹ Virginia's definition, while still situational, does not explicitly take into consideration the attending physician's subjective assessment of the futility of a procedure.⁵⁰ On the contrary, Virginia broadly defines such a treatment as one that does not give a patient a "reasonable expectation of recovery from a terminal condition."⁵¹ Interestingly, Virginia frames such procedures as "life-prolonging,"⁵² whereas Missouri fatalistically labels them "death-prolonging."⁵³ More than semantics, these definitional differences and their respective

proxy if he is a family member of the patient.⁴⁶

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⁴³ VA. CODE ANN. § 54.1-2983.3 (2009 & Supp. 2011).

⁴⁴ Id.

⁴⁵ MO. ANN. STAT. § 404.815 (2011).

⁴⁶ OR. REV. STAT. ANN. § 127.520 (West 2003).

⁴⁷ VA. CODE ANN. § 54.1-2994 (2008 & Supp. 2011).

⁴⁸ See generally MO. ANN. STAT. §§ 190.600–621, 404.800–872 (2011); MO. ANN. STAT. §§ 459.010–055 (2007 & Supp. 2011).

⁴⁹ MO. ANN. STAT. § 459.010 (2007 & Supp. 2011).

 $^{^{50}~}$ Va. Code Ann. § 54.1-2982 (2009 & Supp. 2011).

 $^{^{51}}$ Id.

 $^{^{52}}$ Id.

⁵³ MO. ANN. STAT. § 459.010 (2007 & Supp. 2011).

connotations could make a world of difference to patients whose lives hinge on how such statutes are interpreted.

State codes also vary in their respective preconditions for allowing withdrawal of life-sustaining treatment. Oregon, for example, prohibits a proxy from authorizing the withholding or withdrawing of a lifesustaining procedure unless the patient has a terminal condition, is permanently unconscious, has a condition "which administration of lifesustaining procedures would not benefit the principal's medical condition and would cause permanent or severe pain," or suffers a "progressive, debilitating illness that will be fatal and is in its advanced stages, and the [patient] is consistently and permanently unable to communicate, swallow food and water safely, care for [himself], and recognize [his] family and other people, and there is no reasonable chance that [his] underlying condition will improve."54 Missouri, however, requires that, before a proxy or physician may authorize the withdrawal of lifesustaining support, the proxy must seek information about the medical diagnosis or prognosis.⁵⁵ In addition, if the proxy or physician decides to withdraw ANH, the physician must attempt to explain the intention to do so to the patient as well as the consequences, and give the patient the chance to refuse the withdrawal of the ANH.⁵⁶ If the physician is unable to do so, because the patient is comatose, for example, a certification of the patient's inability to understand must be placed in the patient's file.57

As a result of these discrepancies in states' end-of-life care statutes, patients cannot be sure what to expect from state to state. Worse, yet, individuals who do have advance care directives cannot be sure how those directives may be interpreted from one state to another.

C. Early Efforts to Adopt Uniform Advance Directive Legislation

In 1993, the Uniform Law Commissioners attempted to systemize the fragmented state approaches to regulating advance directives through the UHCDA.⁵⁸ If adopted, the UHCDA allows states to cover living wills, powers of attorney, and decision making standards within one statute, using consistent language, forms, and enforcement standards, and eliminating "cumbersome execution requirements."⁵⁹

⁵⁴ OR. REV. STAT. ANN. § 127.540 (West 2003 & Supp. 2011).

⁵⁵ MO. REV. STAT. § 404.822 (2011).

⁵⁶ Id. § 404.820.

⁵⁷ Id.

⁵⁸ UNIF. HEALTH-CARE DECISIONS ACT (Proposed Official Draft 1993); Charles P. Sabatino, *The New Uniform Health Care Decisions Act: Paving a Health Care Decisions Superhighway*?, 53 MD. L. REV. 1238, 1238–39 (1994).

⁵⁹ See David M. English, The Uniform Health-Care Decisions Act and its Progress in the States, A.B.A. PROBATE & PROPERTY MAGAZINE (MAY–JUNE 2001), http://www.

Furthermore, the UHCDA allows states to modify provisions based on constituents' demands.⁶⁰ Unfortunately, only a few states have taken advantage of the uniform approach by basing their advance directive legislation on the UHCDA.⁶¹ While the differences between states may seem minor at first glance, they complicate already difficult end-of-life decisions for non-residents. First, even if a patient has an advance directive, the medical care provider may have no way of knowing that there is an advance directive on file or of accessing the document.⁶² Even though Medicare and Medicaid healthcare providers must ask if a patient has an advance directive, more than sixty-five percent of the time the physician is not aware that the patient has an advance directive, and more than thirty-five percent of the time cannot find the document.63 While some states have created registries that store patients' advance directives for ready access by healthcare providers, states still differ in how their registries store and access this information.64

In addition, the differences and fragmentation in state legislation are problematic for America's geographically mobile population. As one researcher noted, "Ethical and treatment dilemmas may arise for individuals who become incapacitated in a state other than the state in which their [advance directive] was completed. Some states may mandate that certain provisions for care be specifically mentioned for the agent to make a decision."65 While standardizing state requirements for advance directives does not ensure that an incapacitated patient's wishes will be honored, it will certainly increase such a likelihood.⁶⁶

americanbar.org/publications/probate_property_magazine_home/probate_2001_index/proba $te_may_june_2001_index/rppt_publications_magazine_2001_01mj_01mjenglish.html.$ 60

Id.

⁶¹ See Legislative Fact Sheet - Health-Care Decisions Act, UNIF. LAW COMM'N, http:// www.nccusl.org/LegislativeFactSheet.aspx?title=Health-Care Decisions Act (last visited Nov. 27, 2011) (noting that only Alaska, Hawaii, Maine, Mississippi, New Mexico, and Wyoming have enacted the UHCDA).

⁶² People have been known to store their advance directives in safety deposit boxes, shoeboxes, and any number of other locations that render them inaccessible and useless to physicians in emergency situations. See Allison Hughes, State Advance Directive Registries: A Survey and Assessment, BIFOCAL, Nov.-Dec. 2009, at 23, 36.

⁶³ Id.

⁶⁴ Id. at 38-39. While Louisiana maintains a registry of physical documents, an online database of registrants, and makes copies of the documents accessible only to registrants, family members, or attending healthcare providers, other states make electronic copies of the documents available online. Id. Some of these states, however, only allow access with the individual's code, and others allow access through the patient's name, date of birth, or social security number. Id.

⁶⁵ Gunter-Hunt et al., *supra* note 8, at 55.

⁶⁶ Id.

II. WHY IS IT IMPORTANT TO ESTABLISH A UNIFORM STANDARD AMONG STATES NOW?

A. Available Treatments Will Be Limited—by Default or by Design

In light of these issues, states should act now to adopt a uniform standard for advance directives, especially considering the intertwined factors of the aging population, the crisis in healthcare supply, and changes in healthcare funding. Not only is it likely that the number of Medicare beneficiaries will substantially increase in the near future,⁶⁷ but this aging population is highly mobile and presents challenges of long-term care related to chronic illnesses.

First, it is the population over age sixty-five that most needs to deal with end-of-life care decisions. Statistics show that Medicare beneficiaries represent over eighty percent of deaths.⁶⁸ Second, the majority of these patients suffer from chronic illnesses like heart disease, diabetes, and cerebrovascular disease.⁶⁹ Patients suffering from a chronic illness decline steadily, suffering multiple "health crises" as a result. It is in one of these health crises that a patient may suddenly have to make an important end-of-life care decision. As the Department of Health and Human Services has observed, "At any one of these crises the patient may be close to death, yet there often is no clearly recognizable threshold between being very ill and actually dying."⁷⁰ Although a steady decline in health is anticipated in the chronically ill, severe health crises may not be anticipated, and the patient may suddenly become incapable of making decisions.⁷¹ Having an advance directive in place during these health crises is crucial. Third, it has been reported that "the number of Medicare beneficiaries more than doubled between 1966 and 2004, and is projected to double in size again by 2030 to 78 million."72 These statistics reveal that future healthcare funding will necessarily be stretched thin. Moreover, the increased mobility of the aging population makes it even more necessary that individuals have a portable advance directive document, especially given the variance in state requirements and registries for advance directives.

 $^{^{67}\,}$ A 2004 study by the Agency for Healthcare Research and Quality of the U.S. Department of Health and Human Services found that more than seventy-five percent of Americans currently live past age sixty-five, that eighty-three percent die while covered by Medicare, and that by 2050 the life expectancy for women and men will likely rise to eighty-four and eighty, respectively. LORENZ ET AL., *supra* note 5, at 1.

 $^{^{68}}$ ~2008 REPORT TO CONGRESS, supra note 4, at 1; Kass-Bartelmes & Hughes, supra note 6, at 3.

⁶⁹ Kass-Bartelmes & Hughes, *supra* note 6, at 3.

⁷⁰ Id.

 $^{^{71}}$ Id.

⁷² 2008 REPORT TO CONGRESS, *supra* note 4, at 1.

Perhaps the greatest challenge for the elderly population is the growing demand for access to health care that is increasingly limited in delivery. While analysts disagree as to whether the increasing demand will increase costs and decrease treatments, most at least agree that the availability of healthcare providers will be limited.⁷³ Professor Joseph White argues that the two critical issues in access to health care are the organization of the healthcare system and the availability of healthcare providers.⁷⁴ White asserts that the increase in longevity would not necessarily reduce health care providers.⁷⁵ Others assert that the increase in demand on Medicare as well as a national focus on reducing costs will also limit the availability of treatments.⁷⁶ Regardless of which group is correct, the limited availability of healthcare providers will also limit access to healthcare treatments.

While recent federal healthcare legislation, such as the Patient Protection and Affordable Care Act ("PPACA"), attempts to address the looming increase in costs and imminent shortage of healthcare services,⁷⁷ it does so in a way that is arguably ineffective. In fact, it may only increase patient reluctance to adopt an advance directive. This controversial new legislation attempts to cut costs and eliminate waste by focusing on comparative effectiveness research ("CER")⁷⁸ and

⁷³ CTR. FOR HEALTH WORKFORCE STUDIES, THE IMPACT OF THE AGING POPULATION ON THE HEALTH WORKFORCE IN THE UNITED STATES: SUMMARY OF KEY FINDINGS 2–3 (2006).

⁷⁴ Joseph White, (*How*) Is Aging a Health Policy Problem?, 4 YALE J. HEALTH POL'Y L. & ETHICS 47, 48–49, 68 (2004).

⁷⁵ Id. at 53–54, 57–59, 67–68.

⁷⁶ See Anirban Basu & Tomas J. Philipson, *The Impact of Comparative Effectiveness Research on Health and Health Care Spending* 8 (Nat'l Bureau of Econ. Research, Working Paper No. 15633, 2010), *available at* http://www.nber.org/papers/w15633.

⁷⁷ See Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended in scattered sections of Titles 21, 25, 26, 29, and 42 of the U.S.C.). Federal courts are currently split on the issue of the constitutionality of the PPACA, and after much anticipation, the Supreme Court finally announced on November 14, 2011 that it would hear arguments brought on appeal by twenty-six states and several private parties challenging the controversial legislation. See Mike Sacks, Obama Health Care Law Reaches Supreme Court, With Over Five Hours of Oral Argument Planned, HUFFINGTON POST (Nov. 15, 2011, 11:15 AM), http://www.huffingtonpost.com/2011/ 11/14/obama-health-care-law_n_1092387.html.

⁷⁸ Comparative effectiveness research is intended to help patients and physicians make healthcare decisions "by providing evidence on the effectiveness, benefits, and harms of different treatment options," with "[t]he evidence [being] generated from research studies that compare drugs, medical devices, tests, surgeries, or ways to deliver health care." What Is Comparative Effectiveness Research, AGENCY FOR HEALTHCARE RES. & QUALITY, U.S. DEP'T HEALTH & HUMAN SERVS. http://www.effectivehealthcare. ahrq.gov/index.cfm/what-is-comparative-effectiveness-research1/ (last visited Nov. 27, 2011).

technology.⁷⁹ The law created the Patient-Centered Outcomes Research Institute to conduct CER research.⁸⁰ While some fear that the PPACA combined with attempts to control increasing costs will result in the dreaded "death panels,"⁸¹ according to the American Enterprise Institute for Public Policy Research, the PPACA does not provide for death panels because "[t]hese initiatives neither cut existing benefits nor threaten entrenched interests."⁸² Yet, not only is it unlikely that CER will decrease costs, but its simplistic application may lead to ineffective treatment and increased costs when applied to a heterogeneous population.⁸³ Furthermore, CER does not take into consideration other factors that affect spending and health such as changes in supply and demand for certain treatments.⁸⁴ CER also errs in assuming healthcare treatments can be assessed on a "one size fits all" basis.⁸⁵

Even if CER were a true reflection of the most effective treatment for a patient, it may be applied in a way that limits patients' autonomy

⁸² Scott Gottlieb & Elizabeth DuPre, *The Living Truth about "Death Panels*," AEI HEALTH POLY OUTLOOK, Oct. 2009, at 2, *available at* http://www.aei.org/outlook/100073.

⁸³ Basu & Philipson, *supra* note 76, at 20–21.

⁷⁹ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 6301, 124 Stat. 119, 727 (2010) (codified as amended in scattered sections of Titles 21, 25, 26, 29, and 42 of the U.S.C.); TOMAS J. PHILIPSON & ERIC SUN, PUB. NO. 4, BLUE BILL OR RED PILL: THE LIMITS OF COMPARATIVE EFFECTIVENESS RESEARCH 1–2 (2011).

⁸⁰ PHILIPSON & SUN, *supra* note 79, at 2; Kathryn Nix, *Medicare Chief Favors Rationing*, HERITAGE FOUND. (July 11, 2010), http://www.heritage.org/Research/Commentary/2010/07/Medicare-Chief-Favors-Rationing.

⁸¹ See, e.g., David Catron, *IPAB Is an Acronym for 'Death Panel*,' AM. SPECTATOR (Apr. 22, 2011, 6:09 AM), http://spectator.org/archives/2011/04/22/ipab-is-an-acronym-for-death-p ("[President Obama] no doubt sees PPACA's death panels as a feature rather than a bug. This sentiment is shared of most advocates of socialized medicine. In a piece titled, 'Why "death panels" are a necessary evil,' columnist Jay Bookman captured this progressive consensus when he wrote that 'Death panels exist, they will exist in any conceivable system of health-care delivery, and we all know they are necessary but prefer to ignore it.' For these people, it's either us or Granny....").

 $^{^{84}}$ See id.

⁸⁵ Id. at 21 ("Our analysis of the impact of CER-responsive subsidies suggests that a better understanding is needed as to how CER should be stratified towards obtaining the right treatments for the right subpopulations rather than focused on a 'best' treatment for all patients. It is recognized that 'one size fits all' treatment evaluations may be harmful and the main remedy proposed has been sub-population analysis. However, simply doing a sub-population analysis for many demographic groups neither solves the problem (given within-group heterogeneity) nor is practical in terms of bureaucratic decisionmaking.... When heterogeneity clouds the applicability of centralized studies to individual patients, the 'make or buy'decision of generating evidence on person-specific treatment effects needs to be better understood. An individual ultimately cares about her own treatment effect, the question is how costly it is to learn that effect through personal consumption versus publicly funded CER."); *see also* CONG. BUDGET OFFICE., RESEARCH ON THE COMPARATIVE EFFECTIVENESS OF MEDICAL TREATMENTS: ISSUES AND OPTIONS FOR AN EXPANDED FEDERAL ROLE 21 (2007).

in choosing or even accessing healthcare treatments.⁸⁶ In its March 2010 report on the cost of the PPACA, the Congressional Budget Office ("CBO") cautioned that reducing costs through "payment reductions may not be sustainable in the long term, and could possibly result in diminished quality of care and/or reduce access to needed services."⁸⁷

Dr. Donald Berwick, the interim director of CMS, recommended three steps to guide medical decision-making—three steps that could result in diminished access to services. First, consider whether health intervention is even effective.⁸⁸ Second, consider whether the treatment is more or less effective than comparable treatments.⁸⁹ Third, assess whether the more effective treatment merits the additional cost.⁹⁰ Berwick applied this reasoning in his initial refusal to let Medicare cover the prostate drug Provenge.⁹¹ Prostate cancer patients treated with Provenge were 40% more likely to be alive in three years than those who did not receive it—at a cost of \$90,000 per treatment.⁹² Provenge was finally approved for Medicare coverage in late June 2011.⁹³ Despite Berwick's later assurances that he "abhors rationing," a group of fortytwo senators called for Berwick's removal,⁹⁴ concerned that such a

⁸⁸ Terence P. Jeffrey, *Obama Names Rationing Czar to Run Medicare*, CNSNEWS.COM (May 26, 2010), http://cnsnews.com/node/66655.

⁸⁶ Nix, *supra* note 80 ("[Dr. Donald Berwick] has gone on the record -- several times -- as a passionate supporter of socialized medicine, including the cost-containment decisions that come with it. Whether to allow the government to ration or allow individuals to make their health choices isn't even a question for Berwick -- he claims that 'the decision is not whether or not we will ration care -- the decision is whether we will ration with our eyes open.").

⁸⁷ PATRICIA A. DAVIS ET AL., CONG. RESEARCH SERV., R41196, MEDICARE PROVISIONS IN THE PATIENT PROTECTION AND AFFORDABLE CARE ACT (PPACA): SUMMARY AND TIMELINE 17 (2010). CBO was unable "to determine whether the reduction in the growth rate would be achieved through greater efficiencies in the delivery of health care or if the payment reductions would lead to lower quality of care." *Id.* at 4.

⁸⁹ *Id.*

⁹⁰ Id.

⁹¹ Robert M. Goldberg, *Don Berwick's Death Panel?*, AM. SPECTATOR (Nov. 16, 2010, 6:08 AM), http://spectator.org/archives/2010/11/16/don-berwicks-death-panel. Despite approval by oncology experts at the FDA, the Medicare Coverage Advisory Committee planned to base its decision on an evaluation by the Agency for Health Research and Quality. *Id.* AHRQ's expert opinion, derived from a master's degree in statistics, a Ph.D. in sociology, and a degree in nursing, "determined the FDA data used to approve Provenge was 'adequate' but not entirely convincing." *Id.*

 $^{^{92}}$ Id.

⁹³ Marissa Cevallos, *Prostate cancer treatment Provenge to be covered by Medicare, as is Avastin*, L.A. TIMES (July 1, 2011), http://articles.latimes.com/2011/jul/01/news/la-hebprostate-cancer-provenge-medicare-20110701.

 $^{^{94}\,}$ Robert Pear, Rising Calls to Replace Top Man at Medicare, N.Y. TIMES, Mar. 8, 2011, at A12.

contentious choice to lead CMS would only further undermine the trust of the American people in the healthcare system.⁹⁵

Elected officials have joined various nonprofit groups in the concern that the PPACA will force healthcare providers to ration health care. For example, after holding a hearing to determine whether the law's Independent Payment Advisory Board would interfere with the doctorpatient relationship, Chairman Pitts of the House Health Subcommittee stated that Health and Human Services Secretary Kathleen Sebelius failed "to convince hundreds of medical experts who object to the board on the grounds that it will have the power to slash or completely eliminate coverage for certain treatments."⁹⁶ Likewise, National Right to Life became alarmed by provisions for healthcare rationing in the PPACA, warning the public against the impending, bureaucratic takeover of healthcare decision-making.⁹⁷ Increasing anger and distrust of the federal government's control over health care is evident locally and in Washington.⁹⁸

⁹⁶ Joe Pitts, *Health care reform's poor prognosis*, POLITICO (July 31, 2011, 9:45 PM), http://politico.com/news/stories/0711/60255.html.

⁹⁵ Press Release, U.S. Senate Comm. on Fin., Hatch, Enzi Spearhead Letter to President Urging Him to Withdraw Berwick Nomination to Head CMS (Mar. 3, 2011), *available at* http://finance.senate.gov/newsroom/ranking/release/?id=862493f5-d9d7-418eb47a-17b23142c0b6 ("[T]here are just too many questions about what Dr. Berwick and CMS are doing or will do with the unprecedented power they have been given to reshape our health care system . . . Withdrawing Dr. Berwick's nomination would be a positive first step in rebuilding the trust of the American people. The occupant of this important position, which affects the health care of so many Americans on a daily basis, requires an individual with the appropriate experience and management ability. Our seniors and those who rely on Medicaid deserve no less.").

⁹⁷ ROBERT POWELL CTR. FOR MED. ETHICS, NAT'L RIGHT TO LIFE, LIFE AT RISK: WHAT THE OBAMA HEALTH CARE PLAN MEANS FOR YOU AND YOUR LOVED ONES (2010), available at http://www.stoptheabortionagenda.com/files/RHC2010.pdf ("Basically, doctors, hospitals, and other health care providers will be told by Washington just what diagnostic tests and medical care are considered to meet 'quality and efficiency' standards—not only for federally funded programs like Medicare, but also for health care paid for by private citizens and their nongovernmental health insurance. And these will be standards specifically designed to limit what ordinary Americans may choose to spend on health care so that it is BELOW the rate of medical inflation. Treatment that a doctor and patient deem needed or advisable to save that patient's life or preserve or improve the patient's health but which runs afoul of the imposed standards will be denied, even if the patient is willing and able to pay for it. In effect, there will be one uniform national standard of care, established by Washington bureaucrats and set with a view to limiting what private citizens are allowed to spend on saving their own lives.").

⁹⁸ For instance, after receiving news that a medical center refused to perform surgery on his wife, David Williams threatened to kill President Obama and to blow up the University of Mississippi Medical Center. Jacob Batte, *Mississippi man threatens Obama*, *UMMC*, *held without bond*, DM ONLINE (July 25, 2011, 6:57 PM), http://www.thedmonline.com/article/Mississippi-man-threatens-obama-ummc-held-without -bond; see also Jackie Calmes, *Lawmakers Join Protest Over Bill*, N.Y. TIMES (Nov. 7, 2009,

In addition, certain provisions of the PPACA are problematic for individuals who believe that the PPACA will be used to further limit Medicare patients' access to medical treatment. Specifically, Section 3025 places limits on reimbursements to healthcare providers for "excess readmissions," and further defines a "high-risk Medicare beneficiary" in part by her number of readmissions.⁹⁹ Describing the effect of this provision, one author remarked, "Both of these qualifiers describe more than half the country, making this provision a transparent attempt by government to cut costs by forcibly cutting lives short."¹⁰⁰

Although Section 1233, the Advance Care Planning Counseling provision, was eventually eliminated from the final version of the PPACA, it initially stimulated controversy because of the requirements that it would have placed on physicians' conversations with patients regarding advance directives.¹⁰¹ Section 1233 was intended to give physicians additional motivation and specifications for counseling Medicare patients in advance care planning.¹⁰² This section not only provided for physician reimbursement for time spent in advance care planning consultations, but it also suggested what information physicians should provide patients during consultations.¹⁰³

It is unlikely that Section 1233 really would have assisted physicians, helped patients preserve their autonomy in healthcare decisions, or promoted savings. First, the provisions of Section 1233 would have superseded state and local efforts already aimed at encouraging the implementation of advance directives. As researchers at the American Enterprise Institute for Public Policy Research argued, "Regulation of the practice of medicine historically has been left to states and professional groups. . . . [The provisions of Section 1233] usurp from

¹⁰¹ 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, 410–11 (2010).

^{4:19} PM), http://prescriptions.blogs.nytimes.com/2009/11/07/lawmakers-join-protest-over-bill/.

⁹⁹ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3025, 124 Stat. 119, 408 (2010) (codified as amended in scattered sections of Titles 21, 25, 26, 29, and 42 of the U.S.C.); R. Brent Rawlings et al., *Health Reform for Hospitals and Health Systems*, MCGUIREWOODS 2 (2010), *available at* http://www.mcguirewoods.com/newsresources/publications/health_care/health%20reform%20for%20hospitals.pdf (explaining the effect of the hospital readmissions reduction program of PPACA Section 3025).

¹⁰⁰ John Griffing, *The Deadly Pact: How ObamaCare will 'Save' Money*, AM. THINKER (Aug. 9, 2010), http://www.americanthinker.com/2010/08/the_deadly_pact_how_ obamacare.html ("[Section 3025] gives the Health Secretary the discretion to remove lifeextending treatment from the reach of seniors and place them in state wards for the purposes of making the 'transition' to death as painless as possible. This 'transition' can be activated for virtually any reason, including 'a history of multiple readmissions' or 'risk factor.").

¹⁰² H.R. 3200, 111th Cong. § 1233 (2009).

 $^{^{103}}$ Id.

state and local efforts the authority to regulate aspects of medical practice."¹⁰⁴ Second, Section 1233 would have prompted physicians to go beyond providing information about treatment options as it

mandat[ed] what specific information should be provided to patients. The statutory language actually require[d] . . . that physicians present certain . . . options as being in the patient's clear interest, stating that an "explanation of orders regarding life sustaining treatment or similar orders . . . shall include: the reasons why the development of such an order is *beneficial* to the individual and the individual's family and the reasons why such an order should be updated periodically as the health of the individual changes."¹⁰⁵

In effect, the physician would have been required to tell the patient what healthcare treatment the patient should choose. Third, the narrow provisions may have actually discouraged patients from adopting advance directives and physicians from counseling patients to do so.¹⁰⁶ Ironically, not only was Section 1233 unlikely to promote adoption of advance directives, but it was unlikely to promote savings.¹⁰⁷ It did prompt, however, discussions infused with the fear that changes in health care would result in federally controlled death panels.¹⁰⁸

Even if the PPACA does not impose additional limits or rationing of medical treatments as some have posited,¹⁰⁹ arguably rationing of health care already occurs.¹¹⁰ Some physicians and bioethicists look to rationing as the answer to the funding question, proposing allocation of resources that will necessarily restrict the aging population from receiving certain care. Govind Persad, Alan Wertheimer, and Ezekiel Emanuel from the National Institutes of Health reviewed eight possible methods for allocating healthcare treatments, ultimately recommending the "complete lives system" that combines five, "morally relevant" principles to prioritize who should receive medical treatment: youngest-first, prognosis for recovery, lottery (or random selection), lives saved, and instrumental value.¹¹¹ In their report, these bioethicists propose that a framework discriminating against the aged and very young is morally necessary for a society that "must embrace the challenge of implementing a coherent multiprinciple framework" for allocation of

¹⁰⁴ Gottlieb & DuPre, *supra* note 82, at 6.

 $^{^{105}\,}$ Id. at 5.

¹⁰⁶ *Id.* at 3.

¹⁰⁷ Id.

¹⁰⁸ Perry, *supra* note 101, at 411–12.

¹⁰⁹ See, e.g., Testimony Presented to Congressman Dennis Moore, Myra Christopher, President and CEO, Ctr. for Practical Bioethics 2–3 (Aug. 27, 2009).

¹¹⁰ See Gottlieb & DuPre, supra note 82, at 3.

¹¹¹ Govind Persad et al., Principles for Allocation of Scarce Medical Interventions, 373 LANCET 423, 428 (2009).

healthcare treatment.¹¹² The complete lives system not only discriminates against the aged, but also against infants, based on the "social and personal investment that people are morally entitled to . . . at a particular age."¹¹³ In relation to the youngest-first principle, the three posited.

Adolescents have received substantial education and parental care, investments that will be wasted without a complete life. Infants, by contrast, have not yet received these investments. Similarly, adolescence brings with it a developed personality capable of forming and valuing long-term plans whose fulfilment [sic] requires a complete life. As the legal philosopher Ronald Dworkin argues, "It is terrible when an infant dies, but worse, most people think, when a three-year-old child dies and worse still when an adolescent does."¹¹⁴

In addition, by incorporating the instrumental value principle into their calculation of a "complete life," Persad, Wertheimer, and Emanuel contemplate a system where the fittest are favored over the frail.¹¹⁵ Such "ethics" have no *rightful* place in the American healthcare industry. But, unfortunately, they already have *a* place.

In light of such contemporary, compromising views of ethics, patients nearing the end of their "complete lives" justifiably fear that the conventions they have with their physicians about end-of-life care will be used to reduce costs. While patients who have end-of-life discussions with their physicians are likely to have lower medical costs in their final week of life,¹¹⁶ reducing costs should not be the primary motive for having these discussions.

Rising demands and limited funding in Medicare and Medicaid increase the probability that physicians will not be able to offer patients the treatment they wish to give—much less that patients can receive the treatment they desire to receive. The crisis in funding and reimbursement means that physicians are less inclined to accept Medicare patients, and are restricted in the treatments they can prescribe.¹¹⁷ States will be required to use federal dollars to raise the

¹¹⁷ ROBERT POWELL CTR. FOR MED. ETHICS, NAT'L RIGHT TO LIFE, LIFE AT RISK: HOW THE OBAMA HEALTH CARE PLAN WILL RATION YOUR FAMILY'S MEDICAL TREATMENT - A FACTSHEET 4 (2010), available at http://www.nrlc.org/HealthCareRationing/LifeatRisk Longform.pdf ("Even before the Obamacare cuts, Medicare . . . faced grave fiscal problems as the baby boom generation ages. . . . The consequence will be that the amount of money available for each Medicare beneficiary, when adjusted for health care inflation, will shrink. . . . In theory, taxes could be increased dramatically to make up the shortfall The second alternative—to put it bluntly but accurately—is rationing. Less money

¹¹² *Id.* at 429.

¹¹³ *Id.* at 428.

 $^{^{114}}$ Id.

 $^{^{115}}$ See *id.* at 426.

¹¹⁶ Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 484–85 (2009).

physician Medicaid reimbursement rates in accordance with Medicare rates, costing up to \$68 billion over the next 10 years according to estimates from CBO and CMS.¹¹⁸ But, as The Heritage Foundation points out, federal funding may not be available in the future, and states will be stuck with the bill.¹¹⁹

CMS automatically adjusts reimbursements to physicians based on the Sustainable Growth Rate ("SGR") in order to restrain growing Medicare costs and to ensure that the yearly increase in the expense per Medicare beneficiary does not exceed GDP growth.¹²⁰ However, Congress regularly implements "fixes" to the SGR in an attempt to mollify what would be severely low reimbursements to physicians.¹²¹ Whether or not the fixes should or will continue to be applied in the future is beyond the scope of this Note, but the financial restraints on healthcare providers will surely increase as they treat both Medicare and Medicaid patients.

To comply with the PPACA by 2014, states will have to cover all individuals below 138% of the poverty line with Medicaid.¹²² Physicians in states like Texas with already low physician reimbursement rates will be increasingly unwilling to accept Medicaid and Medicare patients, placing an additional demand on hospital emergency rooms.¹²³ Ultimately, the growth in Medicaid healthcare costs is unsustainable, and it will hit the poorest states the hardest.¹²⁴

¹¹⁸ Brian Blase, Obamacare's Medicaid Policy: Putting the Doctors in Another "Fix," WEBMEMO, Oct. 4, 2010, at 1, available at http://report.heritage.org/wm3031.

 $^{123}\,$ Blase, supra note 118, at 1. Reportedly, already less than one-third of physicians in Texas are active in Medicaid. Id.

¹²⁴ See Robert B. Helms, *Medicaid: The Forgotten Issue in Health Reform*, AEI HEALTH POL'Y OUTLOOK, Nov. 2009, at 2, available at http://www.aei.org/docLib/14-HPO-

available per senior citizen would mean less treatment, including less of the treatments necessary to prevent death. For want of treatment, many people whose lives could have been saved by medical treatment would perish against their will. The third alternative is that, as the government contribution decreases, the shortfall could be made up by voluntary payments from older people themselves, so that their Medicare health insurance premium could be financed partly by the government and partly from their own income and savings.").

¹¹⁹ *Id.* at 3–4.

¹²⁰ *Id.* at 2.

 $^{^{121}\,}$ Id. ("SGR links the increase in Medicare reimbursement rates to growth in GDP. Since medical costs historically increase at a rate more than twice GDP, the SGR reduces the real (inflation-adjusted) payments physicians receive. Congress has overruled this decrease ... 10 times over the past decade, with short-term boosts in Medicare rates above SGR levels.").

¹²² Id. at 1–2. CMS estimates that this will increase Medicaid enrollment by 23 million individuals at a price tag of over \$70 billion. Id. at 2. The Congressional Research Service estimates that coverage will be extended to qualifying individuals with incomes up to 133% of the federal poverty level. HINDA CHAIKIND ET AL., CONG. RESEARCH SERV., R41664, PPACA: A BRIEF OVERVIEW OF THE LAW, IMPLEMENTATION, AND LEGAL CHALLENGES 2 (2011).

Likewise, the growth in Medicare costs is unsustainable, and it will make certain standards unaffordable. While the aging population will increase Medicare costs by 2% over the next 70 years, the overall cost of health care is projected to increase by 6.2%.¹²⁵ The result? The quality of care will inevitably drop as physicians are "squeezed" to provide the required level of care to Medicare patients without assurance of reimbursement.¹²⁶ While there are several models that purport to address the Medicare cost crisis more efficiently,¹²⁷ what are the possible consequences of this squeezing? Specifically, what level of treatment will be available to an elderly population that must deal with chronic illnesses?

While demand for health care will certainly increase with a growing Medicare population, healthcare costs are also likely to increase with increased governmental control of supply—unless supply is limited.¹²⁸ Supply *will* decrease. According to reports by CMS, "[B]y 2017, when [PPACA's] changes are fully phased in, 14.8 million senior citizens and disabled Americans who would have had Medicare Advantage benefits under the previous law will be denied coverage for many services and

¹²⁷ See, e.g., Darius Lakdawalla et al., Addressing Geographic Variation and Health Care Efficiency: Lessons for Medicare from Private Health Insurers, AEI HEALTH POL'Y OUTLOOK, July 2010, at 3, 7–8, available at http://www.aei.org/docLib/2010-7-No-2-g.pdf.

Helms-g.pdf. Medicaid currently covers 20% of the United States population and represents 7% of the federal budget and about seventeen percent of states' budgets. Under the recent health reform measures, these costs will grow at almost 8.5% per year, and will increase from almost 2.5% to 3% of the nation's GDP by 2018. *Id.* at 1.

¹²⁵ White, *supra* note 74, at 51–52.

¹²⁶ John Goodman, *Bending the Cost Curve*, HEALTH AFFAIRS BLOG (Oct. 1, 2010), http://healthaffairs.org/blog/2010/10/01/bending-the-cost-curve ("Once you get past the rhetoric about doctors becoming more 'productive,' you will discover that the new law's mechanism to control Medicare spending is to ratchet down payments to doctors and hospitals. . . . Medicare payment rates will fall below Medicaid rates in 2019 and fall increasingly behind Medicaid in future years. Were there the political will to do this, Medicare enrollees would be getting Medicaid-like services in just a few years and, beyond that, the elderly and the disabled would be in a completely different (and inferior) health care system. The problem is, there is not a not a smidgen of evidence that the political will is there.").

¹²⁸ Goodman, *supra* note 126 ("This is a little-noticed feature of the new law that has been almost completely ignored by everyone The demand for care will almost certainly soar. Start with 32 million to 34 million newly insured people, who will try to double their consumption of care Add to that another 70 million or so who will have much more generous insurance than they currently have. Almost everybody else is promised an array of preventive care services, with no copayment or deductible. How can you have all this newly created demand for care without an enormous increase in health care spending? PPACA's answer: make sure there is no new supply to meet the demand. Although early versions of the bill contained subsidies to increase the number of doctors, nurses and paramedical personnel, these items were all zeroed out before final passage.").

incur higher out-of-pocket costs."¹²⁹ Healthcare providers and states are already faced with an increasingly limited supply of treatments.¹³⁰ They face these limits in hospital rooms at the side of patients who have not articulated or even considered their preferences for end-of-life care. With the incentives to cut corners on health care multiplying, it is more important than ever for patients to unequivocally communicate the type of care they expect to receive. Unfortunately, even if a patient has an advance directive on file, his preference may not be honored. This presents yet another reason set forth below that states must face the need for uniform advance directive legislation now.

B. Advance Directives May Not Reflect a Patient's Wishes—Either on the Document or in Its Enforcement

Simply because a patient puts his preferences in writing in an advance directive does not mean that these preferences will ultimately be honored. While there is always some doubt as to whether a proxy's selection of treatments reflects the patient's wishes, the patient may also have cause to doubt whether his own wishes as articulated in his advance directive will be honored.¹³¹ The Department of Health and Human Services once confirmed this concern, stating that the problem may not be too much care, but instead too little care.¹³² Advance directives have been ineffective in directing care and preempting friction when

families desire life-sustaining treatment for family members in compromised health states (e.g., PVS) [but] providers find the treatment inappropriate. These conflicts may also be the result of philosophical or religious differences. Providers may respond to this situation by attempting to reduce the influence of patient/family preferences on care decisions.¹³³

Ironically, this is the very type of problem advance directives attempt to address. The end-of-life patient is already unable to directly

¹²⁹ Robert A. Book & James C. Capretta, *Reductions in Medicare Advantage* Payments: The Impact on Seniors by Region, BACKGROUNDER, Sept. 14, 2010, at 2, available at http://report.heritage.org/bg2464.

¹³⁰ See NICHOLAS JOHNSON ET AL., CTR. ON BUDGET AND POLICY PRIORITIES, AN UPDATE ON STATE BUDGET CUTS: AT LEAST 46 STATES HAVE IMPOSED CUTS THAT HURT VULNERABLE RESIDENTS AND CAUSE JOB LOSS 1 (2011), available at http://www.cbpp.org/ files/3-13-08sfp.pdf (describing the recession's widespread effects on state budgets, including forcing cuts "that hurt vulnerable residents and cause job loss").

¹³¹ Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers* for Patients Without Advance Directives: A Psychological Critique, 42 GA. L. REV. 979, 997 (2008) ("[R]esearchers consistently find that surrogate decisionmaking on behalf of patients in a variety of health situations frequently does not accurately reflect those patients' actual preferences.").

¹³² See 2008 REPORT TO CONGRESS, supra note 4, at 12–13, 25–26.

¹³³ *Id.* at 12.

communicate his wishes to his physician, and so he has delegated this duty to a proxy. By overriding a proxy's decision—if it is based on a patient's preference—the healthcare provider effectively violates the patient's autonomy. While most states allow physicians to refuse to comply with a patient's wishes because of their religious beliefs or moral convictions,¹³⁴ many states also allow physicians to not comply if they find the treatment medically "futile," "inappropriate," or "ineffective."¹³⁵ In other words, a physician who disagrees with a patient's wishes may refuse to honor them. Many states, such as Texas, defer to hospital or medical ethics committees to determine the course of treatment if there is a conflict.¹³⁶ But even that seemingly neutral act takes the decision away from the patient.

Disabled and minority populations may feel the most vulnerable to a lack of compliance with their wishes. These populations fear that their values are not represented either in the advance directive document itself or in its execution.¹³⁷ In addition, some scholars fear that disabled individuals will be denied more costly treatments if access to health care is based on economic contribution to society.¹³⁸ Based on Persad, Wertheimer, and Emanuel's "complete lives" analysis, these populations have good cause to fear that treatment will be withheld unless they can show that they are making an economic contribution to society.

In addition, proxies' decisions sometimes fail to reflect patients' wishes. Although it is impossible to verify what the patient's actual wishes are after making a final decision to withdraw life-sustaining

¹³⁴ WILL YOUR ADVANCE DIRECTIVE BE FOLLOWED?, *supra* note 27, at 8.

¹³⁵ *Id.* at 7–10.

 $^{^{136}\,}$ Tex. Health & Safety Code Ann. § 166.046 (West 2010 & Supp. 2011).

¹³⁷ 2008 REPORT TO CONGRESS, *supra* note 4, at xii ("[T]here is concern that some clinicians (and infrequently, some family members) of physically disabled individuals undervalue the quality of life of these individuals, and therefore will make decisions concerning life-sustaining care that contrast with what these individuals would want.").

¹³⁸ See, e.g., Mark P. Mostert, Useless Eaters: Disability as Genocidal Marker in Nazi Germany, 36 J. SPEC. EDUC. 157, 169 (2002) ("[R]ecent developments in the United States and Europe are changing the voluntary nature of a 'gentle death' still further, also based, in part, on economic worth. In the United States, Oregon voters have . . . also established economic criteria for who should and who should not receive expensive health care via Medicaid health-care rationing. . . . [T]he Oregon example clearly shows a shift from strict compassion and ethical obligation for treatment of individuals to a more practical medical euthanasia based on collective economic viability. . . . It is important to note that the enactment of prejudice against people with disabilities in Nazi Germany could not have succeeded without the complicity of the medical and adjunct professions. . . . *Currently, there is evidence of the medical community's again being willing agents in hastening the deaths of people deemed not viable, including people with disabilities,* through familiar methods for ending the lives of terminally ill people, such as starvation and death by thirst.") (emphasis added).

treatment,¹³⁹ studies have shown that advance directives are often inadequate in representing an individual's wishes when he is actually faced with an end-of-life decision. For instance, in one study by the Agency for Healthcare Research and Quality of the Department of Health and Human Services, physicians were reportedly only sixty-five percent accurate in representing patients' wishes for treatment, often providing undertreatment.¹⁴⁰ In contrast, proxies' decisions often appeared not to represent end-of-life patients' interests either—but due to overtreatment, not undertreatment.¹⁴¹ Further complicating the matter, patients who were studied often changed their wishes once faced with actual end-of-life questions.¹⁴²

Advance directive documents and discussions could be reformed to more adequately prepare the family or proxy to understand and execute the patient's wishes. Studies indicate that while patients do want to exert some control over end-of-life care issues, they do not necessarily wish to "micromanage" their specific treatments, but prefer to defer to the judgment of a trusted proxy.¹⁴³ To account for such deference, advance directives should allow individuals to specify how much authority they want their proxy to have.¹⁴⁴ The advance directive may also be more successful in reflecting the patient's wishes if the document includes a "wider scope of values and goals the patients feel are most important in life."¹⁴⁵

No matter how clearly the document expresses the patient's wishes, the patient and the proxy's decisions depend on what information is made available by the physician and how. Not only may the document and the proxy be inadequate or ill-prepared to represent the patient's interest, but the patient herself may be inadequately counseled about her medical future living with her health condition.¹⁴⁶ First, physicians

¹³⁹ See Michael R. Flick, *The Due Process of Dying*, 79 CALIF. L. REV. 1121, 1143 (1991) ("In that destruction [of the person for whom the choice is made], autonomy is perversely, and inexplicably, said to be vindicated. The vexation of uncertainty is removed by an exercise of power. The victim, destroyed, cannot complain. The decisionmaker is anesthetized by the powerlessness of having made the only rational choice. . . . The responsibility for the decision rests on [the] victim.").

¹⁴⁰ Kass-Bartelmes & Hughes, *supra* note 6, at 2.

¹⁴¹ Id.

 $^{^{142}}$ Id. at 4 ("[P]atients often changed their minds when confronted with the actual situation or as their health status changed. Some patients who stated that they would rather die than endure a certain condition did not choose death once that condition occurred.").

¹⁴³ Nikki Ayers Hawkins et al., *Micromanaging Death: Process Preferences, Values,* and Goals in End-of-Life Medical Decision Making, 45 GERONTOLOGIST 107, 116 (2005).

¹⁴⁴ *Id.*

 $^{^{145}}$ Id.

¹⁴⁶ See Temkin-Greener et al., supra note 25, at 687–89.

often lack adequate time and training to provide counseling.¹⁴⁷ Nevertheless, they are expected to give not only objective recommendations for medical treatment, but also an ethical evaluation of the possible treatments based on the patient's best interest.

Physicians have historically and commonly been accepted as the best individuals to provide counseling regarding end-of-life care treatments and decision-making.¹⁴⁸ As healthcare choices become increasingly complex and technical, patients are especially susceptible because they will tend to give even more deference to physicians' expertise.¹⁴⁹ The American Medical Association and medical schools do provide physicians and students with general ethical guidelines to help proxies make decisions.¹⁵⁰ Yet, with decreasing supply of healthcare professionals and medical attention, increasing demand for health care, and increasing costs, the patient should be wary of placing complete trust in the physician's ability to provide objective counseling.¹⁵¹

Second, patients may also be at risk because of difficulties physicians encounter in helping patients make medical choices. Although the Liaison Committee on Medical Education requires medical schools to include end-of-life care in their curriculum,¹⁵² there is room for improvement according to responses recently obtained from medical

 $^{^{147}}$ Id. at 688 ("Most physicians, and other health care professionals, receive very cursory, if any, school training in either end-of-life discussions or in patient-interviewing techniques.").

¹⁴⁸ See David J. Rothman, *Revisionism Misplaced: Why This Is Not the Time to Bury Autonomy*, 97 MICH. L. REV. 1512, 1514 (1999) (reviewing CARL E. SCHNEIDER, THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS (1998) (explaining from poll data, sociological surveys, and patient memoirs that critically ill patients often turn to their doctor for counseling on the most difficult health decisions)).

 $^{^{149}\,}$ Id. at 1516.

¹⁵⁰ See, e.g., COUNCIL ON ETHICAL & JUDICIAL AFFAIRS, AM. MED. ASS'N, CODE OF MEDICAL ETHICS 223 (2004–2005) ("In general, physicians should respect decisions made by the appropriately designated surrogate on the basis of sound substituted judgment reasoning or the best interest standard. In cases where there is a dispute among family members, physicians should work to resolve the conflict through mediation. Physicians or an ethics committee should try to uncover the reasons that underlie the disagreement and present information that will facilitate decision making. When a physician believes that a decision is clearly not what the patient would have decided or could not be reasonably judged to be within the patient's best interests, the dispute should be referred to an ethics committee before resorting to the courts.").

 $^{^{151}}$ Rothman, *supra* note 148, at 1519 ("When physicians must see patients on a tenminute schedule, and when financial conflict of interest is more acute now in medicine than ever before, I do not think it wise, in individual or policy terms, to worry about an excess of reliance on patient decisionmaking. Indeed, I cannot think of a worse time to champion the idea of passive patients.").

¹⁵² LIAISON COMM. ON MED. EDUC., FUNCTIONS AND STRUCTURE OF A MEDICAL SCHOOL: STANDARDS FOR ACCREDITATION OF MEDICAL EDUCATION PROGRAMS LEADING TO THE M.D. DEGREE 9 (2011), *available at* http://www.lcme.org/functions2011may.pdf.

students.¹⁵³ Medical students are trained to focus on getting patients to tell doctors what doctors need to know—not vice versa, and some critics argue that in reality it is impossible to separate "value choices" (decisions that, in theory, only patients should make) from "technical choices" (decisions physicians would make).¹⁵⁴

Healthcare professionals themselves are learning about new treatment mechanisms, and are expected not only to be able to decipher which treatments are most effective, but also to communicate to patients what treatment would have the most "meaningful" outcome.¹⁵⁵ Although physicians themselves are on a "learning curve," they are still in the best position to recommend treatments, as opposed to federal or state agencies that are really just trying to deal with rising Medicare and Medicaid costs. Physicians should not have to recommend only a single "best" healthcare option, but rather encourage patient autonomy by discussing a range of treatment options, allowing the patient or proxy to properly make the decision.¹⁵⁶

While historically the physician has been the most qualified individual to recommend specific treatments, she also has an overwhelming level of discretionary power. She has great discretion, not only in recommending levels of treatments for the patient to adopt as part of the advance directive, but also for the proxy to approve when the patient is incapacitated. How much discretion the physician will have, however, likely depends on the predictive outcomes of CER.¹⁵⁷

In addition, because individuals often do not take time to consider healthcare options until they face a medical crisis, counseling for advance directives often happens when the patient is perhaps the least emotionally prepared to deal with these issues. Patients at this point are often facing depression, have just been diagnosed with a terminal illness, or were admitted to a healthcare facility due to a sudden illness.¹⁵⁸ Patients are therefore vulnerable not only to the physician's counsel, but also to family social pressure and depression.¹⁵⁹ They may be easily

¹⁵³ Thomas J. Papadimos et al., An Overview of End-of-Life Issues in the Intensive Care Unit, 1 INT'L J. CRITICAL ILLNESS & INJ. SCI. 138, 138–46 (2011).

¹⁵⁴ Rothman, *supra* note 148, at 1516.

¹⁵⁵ See, e.g., Jackson P. Rainer & Patti Ellis McMurry, *Caregiving at the End of Life*, 58 J. CLINICAL PSYCHOL. 1421, 1425 (2002) ("As one home-health nurse said, 'We're on a learning curve. We've learned that modern technology has its role in treating some patients and not in treating others. Sure, we've got all kinds of fancy tools, but we've got to learn to use these tools when they can make a difference that's meaningful.").

¹⁵⁶ See supra note 86 and accompanying text.

¹⁵⁷ See LIFE AT RISK, supra note 117, at 5.

¹⁵⁸ Kass-Bartelmes & Hughes, *supra* note 6, at 2–4.

¹⁵⁹ One neurologist creatively introduced the merits of physician-assisted suicide, which is often induced by family and social pressure on end-of-life patients, through a fictional discussion between a physician and friends that highlighted how physician-

coerced into thinking that they will be a burden on family and society, and that a decision to forego medical treatment would be the most moral and considerate choice.¹⁶⁰ As noted earlier, the physician's judgment may also be clouded by economic concerns as a result of limits in reimbursement.¹⁶¹

While there is no perfect way to protect patients' interests, advance directives that express patients' wishes—either in writing or through a proxy—go a long way to protect patients when they are most vulnerable and are unable to express their wishes. States should consider noncoercive ways to encourage residents to adopt advance directives well before they are faced with medical treatment. The differences among states in form, content and registry; the increasing cost and demand for health care; the growing elderly population; and dubious enforcement all point to a need for reform and uniformity of advance directives. This uniformity, however, must happen at the state level.

III. WHY ADVOCATE FOR UNIFORMITY AT THE STATE LEVEL?

State legislatures should work together to adopt not only uniform documents for advance directives, but also uniform protocols for counseling patients in completing forms and proxies in making end-oflife care decisions. Because under federal law states retain the right to determine the form and requirements for advance directives,¹⁶² states are in the best position to identify patients' needs and address their concerns through legislation. Through avenues such as the National Conference of State Legislatures, the American Legislative Exchange Council, and the National Conference of Commissioners on Uniform

 161 Trew, *supra* note 12, at 300 ("With the cost of health care continuing to rise in the United States, health care providers could face the dangerous temptation to 'persuade chronic patients to minimize costs by ending it all painlessly.").

¹⁶² 42 U.S.C. § 1395cc(f) (2006).

assisted suicide can purportedly avoid family anguish. C. William Britt, Jr., *Reflections for May: Buster's View*, 76 NEUROLOGY 1677, 1678 (2011) ("When someone gets diagnosed with a terminal condition, why not tell them medication for suicide is available?... That way they can pick the time they die, work it out with their family and the doctors. There wouldn't be the shock to these families.").

¹⁶⁰ See, e.g., Rita L. Marker et al., Euthanasia: A Historical Overview, 2 MD. J. CONTEMP. LEGAL ISSUES 257, 269 (1991) (quoting from a popular 1930s Nazi propaganda novel in which a doctor on trial for killing his crippled wife at her request defended himself by suggesting, "Would you, if you were a cripple, want to vegetate forever?"); ROBERT PEARLMAN ET AL., YOUR LIFE, YOUR CHOICES: PLANNING FOR FUTURE MEDICAL DECISIONS: HOW TO PREPARE A PERSONALIZED LIVING WILL 21, available at http://www.life issues.org/euthanasia/pdf/your_life_your_choices.pdf. The booklet by Robert Pearlman entitled Your Life, Your Choices offers an exercise for determining whether one's life is "worth living" based on a series of factors in a checklist, such as being no longer able to walk, get outside, or contribute to a family's well-being. The factors also include the need for long-term care, living in a nursing home, or causing severe emotional and financial burdens on a family. Id.

State Laws ("NCCUSL"), states have already been able to effectively address regulatory needs by multi-state legislation.¹⁶³ As noted earlier, the NCCUSL has already proposed the UHCDA, which several states have adopted as the basis for their advance directive laws.¹⁶⁴ Just like multi-state legislation such as the Uniform Commercial Code, which has been adopted and effectively implemented by all fifty states after a drafting period of ten years, state legislatures can likewise work with state and national organizations to refine the UHCDA.

In addition, states could retain the ability to include limitations and allowances unique to their states. For example, by creating a multi-state form and registration process for advance directives, states that do not permit physician assisted suicide still could include provisions that explicitly prevent visitors to their state from receiving this treatment. Meanwhile, states that do allow for the treatment may include a warning to their own citizens that the particular treatment is only available in their states.

West Virginia's Initiative to Improve End-of-Life Care provides an example of a state that effectively took steps to address a statewide problem concerning adequately respecting end-of-life wishes. Alarmed by the low rate of use of hospice care, West Virginia created a task force in 2000 with representatives from the state nursing home association, hospice council, and the state office of health facility licensure and certification.¹⁶⁵ After finding that Medicaid had "created a financial disincentive for nursing homes to enroll residents in hospice" despite their wishes, the task force convinced Medicaid to change its policy, causing hospice enrollment to increase by 400% within a short time.¹⁶⁶ In addition, the state initiated the Healthy People 2010 program that includes, among its 300 objectives, a goal of increasing the percentage of people who complete written advance directives to 50%.¹⁶⁷ This example from West Virginia is just one of many that demonstrates that states best know their residents and their health needs, and why it is state legislatures who must create uniform advance directive regulations, not the federal government.

¹⁶³ James M. Thunder, *Strengthening Federalism*, AM. SPECTATOR (Nov. 16, 2010, 6:08 AM), http://spectator.org/archives/2010/11/16/test.

¹⁶⁴ UNIF. HEALTH-CARE DECISIONS ACT (Proposed Official Draft 1993); see also, e.g., ALASKA STAT. §13.52 (2010); DEL. CODE ANN. tit. 16, § 25 (2003 & Supp. 2010); HAW. REV. STAT. § 327E (2008 & Supp. 2010); ME. REV. STAT. ANN. tit. 18–A, §§ 5-801 to -817 (1998 & Supp. 2010).

¹⁶⁵ Data-Driven Policymaking (An Update): Using Statistics to Shape Agendas and Measure Progress, STATE INITIATIVES IN END-OF-LIFE CARE, Feb. 2003, at 2–3.

¹⁶⁶ *Id.* at 3.

¹⁶⁷ Id.

IV. WHAT EXISTING FORMS PROVIDE A MODEL?

The current UHCDA (1) establishes when advance directives will be enforced,¹⁶⁸ (2) sets out "best interest" as the standard for agents' decision-making in the absence of instructions from a patient,¹⁶⁹ (3) describes when an advance directive may be revoked,¹⁷⁰ and (4) provides a model form that allows both the nomination of a power of attorney for health care or agents, as well as specific instructions for any aspect of the patients' health care.¹⁷¹ The UHCDA is a helpful model because it provides one form that allows patients to designate their proxy and to specify desired treatments.

In addition, the "Five Wishes" form, although it does not provide model legislation, meets the requirements of forty-two states regarding advance directives.¹⁷² Created by Aging with Dignity together with the assistance of the American Bar Association Commission on Law and Aging, Five Wishes is written in plain, everyday language and allows patients to decide their proxy, the kind of medical treatment they do or do not want, how comfortable they want to be, how they want people to treat them, and what they want their loved ones to know.¹⁷³ Five Wishes provides a complete booklet with forms for very little cost to interested patients.¹⁷⁴ A 2009 Wall Street Journal article providing an overview of advance directive options highlighted satisfied individuals who had completed the Five Wishes document.¹⁷⁵ Five Wishes's strength appears to be that it is readily available and understandable for individuals even without explanation. Despite its strengths, Five Wishes has been criticized by some practitioners who warn that it "should not be used as a replacement for statutory advance directives because it contains legally ambiguous language and may conflict with the authority delegated under [another portion of the state's law]."¹⁷⁶ Unfortunately, the document was rejected by Veterans' Affairs ("VA") in exchange for

¹⁶⁸ UNIF. HEALTH-CARE DECISIONS ACT, § 10 cmt. at 29–30.

¹⁶⁹ *Id.* § 2(e).

¹⁷⁰ Id. § 3.

¹⁷¹ Id. § 4.

¹⁷² Five Wishes, AGING WITH DIGNITY, http://www.agingwithdignity.org/five-wishes. php (last visited Nov. 27, 2010).

 $^{^{173}}$ Id.

 $^{^{174}}$ Id.

¹⁷⁵ Melinda Beck, *Preparing for the Final Hours*, WALL ST. J., Aug. 18, 2009, at D2.

¹⁷⁶ Ray J. Koenig III & Mackenzie Hyde, *Be Careful What You Wish For: Analyzing the "Five Wishes" Advance Directive*, 97 ILL. B.J. 242, 243 (2009) (arguing that Five Wishes, though helpful in prompting dialogue about end-of-life care, is not a proper substitute for statutory advance directives under Illinois law as it may create ambiguities and conflicting interests).

VA's adoption of the controversial booklet, *Your Life, Your Choices*.¹⁷⁷ Five Wishes remains, however, independent and compliant with most state documents and requirements.

NRL's "Will to Live" project likewise proposes a document not attached to any one state. Will to Live was created with the express purpose of protecting patients from being denied medical care.¹⁷⁸ NRL's Will to Live, in contrast with the UHCDA or Five Wishes, explains to patients, among other things, that the terminology used in most advance directives forms, such as "excessive pain" or "excessive burden," has specific legal consequences and must be carefully selected.¹⁷⁹

None of these three documents singularly addresses the need for a uniform advance directive form. Of the three, the UHCDA provides the best model for a uniform document. The drawback of the UHCDA, however, is that it does not offer the plain language and user-friendly approach of the Five Wishes document, nor does it include the protective language of the Will to Live form. While patients should be able to understand the language of an advance directive apart from the counseling of a physician or attorney, they must also be aware of the legal consequences not only of word choice but of the implications of CER and limits in healthcare funding. NRL's Will to Live form attempts to offer such explanations. Ideally, states should draw upon the strengths of all of three documents, formulating a composite of these three (and perhaps other) documents in order to achieve legislation that allows for a uniform advance directive that is informative, clear, and user-friendly.

¹⁷⁷ Jim Towey, Your Life Is Not Worth Living: the frightening message a VA document sends to aging veterans, NAT'L REV. ONLINE (Sept. 9, 2009, 4:00 AM), www.nationalreview.com/articles/228199/your-life-not-worth-living/jim-towey.

¹⁷⁸ Why Not Sign a Living Will Instead of the Will to Live?, NAT'L RIGHT TO LIFE, http://www.nrlc.org/euthanasia/willtolive/WhynotWTL.html (last visited Nov. 27, 2011) ("The bottom line is this: if you are someone who doesn't want medical technology to prolong your last hours, but who also doesn't want to be starved or allowed to die just because you have a disability, your wishes will be far more likely to be respected if you sign a properly prepared Will to Live than if you sign a living will.").

¹⁷⁹ ROBERT POWELL CTR. FOR MED. ETHICS, NAT'L RIGHT TO LIFE, SUGGESTIONS FOR PREPARING WILL TO LIVE DURABLE POWER OF ATTORNEY, at ii (rev. 2008), *available at* http://www.nrlc.org/euthanasia/willtolive/docs/virginia.rev1208.pdf (last visited Nov. 27, 2011) ("[D]o not use language rejecting treatment which has a phrase like 'excessive pain, expense or other excessive burden.' Doctors and courts may have a very different definition of what is 'excessive' or a 'burden' than you do. Do not use language that rejects treatment that 'does not offer a reasonable hope of benefit.' 'Benefit' is a legally vague term. If you had a significant disability, a health care provider or court might think you would want no medical treatment at all, since many doctors and judges unfortunately believe there is no 'benefit' to life with a severe disability.").

V. WHY SHOULD STATES ACT NOW?

One of the most critical ethical issues of our time, end-of-life healthcare decisions, depends on what healthcare options are available to the decision maker. Despite the best efforts of proxies to comply with patients' wishes, absent assurance that these wishes can be complied with, advance directives are meaningless. In light of an increase in the Medicare-eligible population, reduced funding for Medicare and Medicaid, encouraged dependence on CERs, and the dubious enforcement of existing advance directives, states should act now to protect their citizens' healthcare interests.

With only eighteen to thirty-six percent of the population having adopted an advance directive,¹⁸⁰ and with the looming reality of rationed healthcare, states have a narrow window to reform existing laws so that advance directives are accessible to patients and physicians, uniform in requirement, easy to understand, protective of patients' wishes, and uniform in enforcement. State legislatures should begin working together to develop a multi-state law similar to the UCC. They should not repeat the VA's error in using *Your Life, Your Choices*, a publication created by authors from the Hemlock Society, adopted amidst controversy and after protest from experts in the field.¹⁸¹

Instead, states should develop model legislation with the counsel of entities that represent the interests of disabled, pro-life, minority, and religious communities, and with the counsel of physicians and other healthcare providers. The involvement of these communities does not guarantee that individuals in those communities will adopt advance directives. It will, however, force legislatures to consider their perspectives and knowledge, and may increase the rate of adoption of advance directives.

CONCLUSION

States should work together to develop uniform regulations for advance directives that address the concerns raised by individual patients and scholars alike. They should do so in consultation with certain groups such as the disabled community who are most affected by government regulations of advance directives. The regulations' forms should use plain, everyday language but also provide legal definitions so the patient using the advance directive can understand the legal impact of each statement. It should also include a "will to live," allowing the patient to stipulate which treatments may never be withheld. In addition, states should develop a national registry of advance directives

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¹⁸⁰ 2008 REPORT TO CONGRESS, *supra* note 4, at 13.

¹⁸¹ See Towey, supra note 177 and accompanying text.

that is accessible to the patient and the treating physician in any state. Finally, apart from conflicts with existing state law or the physician's value-based objection, the advance directive should be honored. Although uniform legislation will not ensure that each patient's wishes are known and respected, it will address the need for clarity, consistency, and the ability of patients to use advance directives to protect their health care and their lives.

Ruth F. Maron¹⁸²

¹⁸² I am grateful to the *Regent University Law Review* staff and board members for their hard work and especially to my mother, Maureen Maron, and family for their constant encouragement, prayers, and support.

State	Statutes*	Title	When AD/Other Document Is Triggered	Honor Other States' Documents?
AL	ALA. CODE §§ 22- 8A-1 to -14 (LexisNexis 2006).	Natural Death	P cannot understand or direct medical treatment; two physicians determine terminal illness or unconscious. § 22-8A- 4.	Yes, unless not in compliance with AL law. § 22-8A-12.
AK	ALASKA STAT. §§ 13.52.010–.395 (2010).	Health Care Decisions	P lacks capacity; determined by primary physician or court (mental illness).	Yes, unless not in compliance with AK law. § 13.52.010.
AZ	ARIZ. REV. STAT. ANN. §§ 36-3201 to -3297 (2009 & Supp. 2011).	Living Wills and Health Care Directives	P is unable to make or communicate healthcare treatment decisions. § 36-3231.	Yes, to the extent that it does not conflict with the criminal laws of AZ. § 36-3208.
AR	ARK. CODE ANN. §§ 20-17-201 to -218 (2005 & Supp. 2011).	Rights of the Terminally Ill or Permanently Unconscious	P in TC and cannot make decisions regarding LST or is permanently unconscious; two physicians determine. § 20-17- 203.	Yes. § 20-17-212.
CA	CAL. PROB. CODE §§ 4600–4806 (West 2009).	Health Care Decisions	P lacks capacity. § 4682.	Yes. § 4676.
CO	COLO. REV. STAT. §§ 15-14-503 to -509, 15-18-101 to -113, 15-18.5-101 to -105 (2011).	Patient Autonomy; Medical Treatment Decision	P lacks decisional capacity; determined by attending physician or APRN. §15-18.5- 103.	Yes, presumed to comply. § 15-14-509.
СТ	CONN. GEN. STAT. ANN. §§ 19a-570 to -580g (West 2011).	Removal of Life Support Systems	P incapacitated; determined by attending physician. § 19a-579.	Yes, if not contrary to public policy. § 19a-580g.
DE	DEL. CODE ANN. tit. 16, §§ 2501–2518 (2003 & Supp. 2010)	Health-Care Decisions	P lacks capacity; determined by primary or other physicians; DPAHC may accommodate P's beliefs and designate another person other than physician to certify in notarized document. § 2503.	Yes. § 2517.
DC	D.C. CODE §§ 21- 2202 to -2212 (2001 & Supp. 2011).	Health-Care Decisions	P incapacitated; determined by one physician and one other physician or healthcare professional. § 21-2204.	

TABLE 1: COMPARISON OF SELECT STATE LEGISLATION FOR ADVANCE DIRECTIVES AND SURROGATE DECISION-MAKING^{*}

^{*} Table 1 is intended to serve only as a guide to relevant state code sections and is not a comprehensive listing of all state statutes that are implicated by advance directives or similar legislation. Key words and phrases are abbreviated throughout the table as follows:

AD	"Advance Directive"
(AP)NP	"(Advanced Practice) Nurse Practitioner"
(AP)RN	"(Advanced Practice) Registered Nurse"
(D)PAHC	"(Durable) Power of Attorney for Health Care"
Р	"Principal, Declarant, Patient"
PA	"Physician's Assistant"
PVS	"Permanent Vegetative State"
LST	"Life-sustaining Treatment"
TC	"Terminal Condition"

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FL	FLA. STAT. ANN. §§ 765.101–.113 (West 2010 & Supp. 2012).	Health Care Advance Directives	P lacks capacity; determined by attending physician or two physicians if in doubt. § 765.204.	Yes. § 765.112.
GA	GA. CODE ANN. §§ 31-32-1 to -14 (2009 & Supp. 2011).	Advance Directives for Health Care	9 in TC or permanently unconsciousness. §§ 31-32-5, - 9.	Yes. § 31-32-5.
ні	HAW. REV. STAT. ANN. §§ 327E-1 to -16, 327K-1 to -4 (LexisNexis 2008 & Supp. 2010).	Health-Care Decisions; Physician Orders for Life- Sustaining Treatment	P lacks capacity; determined by primary physician. § 327E- 3.	Likely yes (seeks uniform application among states enacting law). § 327E-15.
ID	IDAHO CODE ANN. §§ 39-4501 to -4515 (2011)	Medical Consent and Natural Death	P not able to communicate healthcare wishes. § 39-4509.	Yes, if it substantially complies with ID law. § 39-4514.
IL	755 ILL. COMP. STAT. ANN. 35/1 to /10, 40/1 to /65, 45/4-1 to -12 (West 2007 & Supp. 2011)	Living Will; Health Care Surrogate Act; Powers of Attorney for Health Care	P incapacitated or has a qualifying condition. 40/20.	Yes. 35/9.
IN	IND. CODE ANN. §§ 16-36-4-0.1 to -21 (LexisNexis 2011); IND. CODE ANN. §§ 30-5-5-16 to -17 (LexisNexis 2000 & Supp. 2011).	Living Wills and Life Prolonging Procedures; Powers of Attorney	P cannot consent or communicate preferences for health care. §§ 30-5-5-16, -17.	Yes, if executed according to IN law. §16-36-4-14.
IA	IOWA CODE ANN. §§ 144A.1 to .12, 144B.1 to .12 (West 2005 & Supp. 2011).	Life-Sustaining Procedures; Durable Power of Attorney for Health Care	P cannot make healthcare decisions; physician determines. § 144B.5.	Yes, as consistent with IA law. § 144B.3.
KS	KAN. STAT. ANN. §§ 58-625 to -632 (2005 & Supp. 2010); KAN. STAT. ANN. §§ 65-28,101 to -28,109 (2002 & Supp. 2010).	Durable Power of Attorney for Health Care Decisions; Natural Death	P incapacitated or suffers disability (DPAHC). § 58-625.	Yes, but actions by healthcare providers must comply with KS law. § 58-630.
КҮ	Ky. Rev. StAr. ANN. §§ 311.621– .643 (LexisNexis 2007 & Supp. 2011).	Living Will Directive Act	Attending physician determines P lacks decisional capacity. § 311.629.	Yes, as consistent with accepted medical practice. § 311.637.
LA	LA. REV. STAT. ANN. §§ 40:1299.58.1 to .10, 40:1299.64.1 to .6 (2008 & Supp. 2011).	Declarations Concerning Life- Sustaining Procedures; Physician Order for Scope of Treatment	P comatose, incompetent, or otherwise cannot communicate. § 40:1299.58.5.	Yes. § 40:1299.58.10.
ME	ME. REV. STAT. ANN. tit. 18, §§ 5- 801 to -818 (1998 & Supp. 2010).	Uniform Health- Care Decisions Act	P lacks capacity; primary physician determines. §§ 5- 802, -811.	Likely yes (seeks uniform application among states enacting law). § 5-815.
MD	MD. CODE ANN., HEALTH-GEN. §§ 5- 601 to -618 (LexisNexis 2009 & Supp. 2011).	Health Care Decisions	P incapable of making informed decision for health care; certified by treating and other physician. § 5-602.	Yes, as conforms with MD law. § 5-617.

WHO HAS A WILL TO LIVE?

	1		1	1
МА	MASS. GEN. LAWS ch. 201D, §§ 1–17 (West 2004 & Supp. 2011).	Health Care Proxies	P lacks capacity to make or communicate healthcare choices; determined by attending physician. § 6.	Yes, as complies with MA law. § 11.
MI	MICH. COMP. LAWS ANN. §§ 333.5651– .5661 (West 2001 & Supp. 2011); MICH. COMP. LAWS §§ 700.5501–5520 (West 2002 & Supp. 2011).	Dignified Death; Durable Power of Attorney	P in advanced illness. § 333.5655. P cannot participate in medical treatment decisions; determined by attending and other physician or psychologist. § 700.5508.	
MN	MINN. STAT. ANN. §§ 145B.01–.17, 145C.01–.16 (West 2011).	Living Will; Health Care Directives	Effective when P, as determined by the attending physician, lacks decision- making capacity to make healthcare decision or as otherwise specified by P. § 145C.06.	Yes, if substantially complies with MN law. § 145B.16.
MS	MISS. CODE ANN. §§ 41-41-201 to -229 (2009 & Supp. 2011)	Health-Care Decisions	Primary physician determines or is informed that P lacks capacity. § 41-41-215.	Yes, as conforms with MS law. § 41-41-205.
МО	MO. ANN. STAT. §§ 404.800865 (West 2011); MO. ANN. STAT. §§ 459.010055 (West 2007 & Supp. 2011).	Durable Power of Attorney for Health Care; Declarations, Life Support	P incapacitated; certified by two physicians; must be periodically reviewed. § 404.825.	
МТ	MONT. CODE ANN. §§ 50-9-101 to -505 (2011).	Rights of the Terminally Ill	P in TC and cannot make decisions regarding LST; determined by attending physician or APRN. § 50-9-105.	Yes, if substantially similar to MT law. § 50- 9-111.
NE	NEB. REV. STAT. ANN. §§ 20-401 to -416 (LexisNexis 2008); NEB. REV. STAT. ANN. §§ 30- 3401 to -3432 (LexisNexis 2010).	Rights of the Terminally Ill; Health Care Power of Attorney	P in TC or PVS, cannot make decisions for LST, and attending has tried to notify family member. § 20-405. P incapable of making medical treatment decisions. § 30-3401.	Yes. § 20-414.
NV	NEV. REV. STAT. ANN, §§ 162A.700– .860 (LexisNexis 2009); NEV. REV. STAT. ANN. §§ 449.535–690 (LexisNexis 2009); NEV. REV. STAT. ANN, §§ 450B.400– .590 (LexisNexis 2009).	Durable Power of Attorney for Health Care Decisions; Rights of the Terminally III; Withholding Life Sustaining Treatment	DPAHC effective when document is executed unless document provides that it becomes effective on a certain day or P incapacitated; incapacity determined by physician, psychiatrist, or psychologist. § 162A.810. Living will operative when P in TC and cannot make decisions regarding LST, § 449.617.	Yes, if in compliance with NV law. § 449.690.
NH	N.H. REV. STAT. ANN. §§ 137-J:1 to -J:33 (LexisNexis 2006 & Supp. 2010).	Written Directives for Medical Decision Making for Adults Without Capacity to Make Health Care Decisions	P lacks capacity to make healthcare decisions; certified by attending physician or APRN. § 137-J:5.	Yes, execution must comply with NH law § 137-J:17.
NJ	N.J. STAT. ANN. §§ 26:2H-53 to -91 (West 2007 & Supp. 2011).	Advance Directives for Health Care	P lacks capacity to make healthcare decisions; determined by attending physician; confirmed by another physician (but not needed if incapacity clearly apparent). § 26:2H-59, -60.	Yes. Also recognizes AD executed in foreign country if not contrary to public policy. § 26:2H-76.
NM	N.M. STAT. ANN. §§ 24-7A-1 to -18 (West 2003 & Supp. 2010).	Uniform-Health Care Decisions	P lacks capacity; determined by primary and other physician. § 24-7A-11.	Yes, enforced to extent if made in NM. § 24-7A-16.

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NY	N.Y. PUB. HEALTH LAW §§ 2980–2994 (McKinney 2007 & Supp. 2011).	Health Care Agents and Proxies	P lacks capacity; determined by attending physician. §§ 2981, 2983.	Yes. § 2990.
NC	N.C. GEN. STAT. ANN. §§ 32A-15 to -27 (West 2008 & Supp. 2010); N.C. GEN. STAT. ANN. §§ 90-320 to -323 (West 2008 & Supp. 2010).	Health Care Powers of Attorney; Right to Natural Death; Brain Death	P lacks capacity; determined by attending physician. If P has religious objections, P may designate agent to certify lack of capacity before notary. § 32A-20.	Yes. § 32A-27.
ND	N.D. CENT. CODE §§ 23-06.5-01 to -19 (2002 & Supp. 2011).	Health Care Directives	P lacks capacity; certified by attending physician. § 23-06.5- 03.	Yes. § 23-06.5-11.
ОН	OHIO REV. CODE ANN, §§ 1337.11– .17 (LexisNexis 2006 & Supp. 2011); OHIO REV. CODE §§ 2133.01–.26 (LexisNexis 2007 & Supp. 2011).	Durable Power for Health Care; Rights of the Terminally III and the DNR Identification and Do-Not- Resuscitate Order	DPAHC in effect when P lacks capacity; determined by attending physician. § 1337.13. Declaration for LST operative when P in TC, permanently unconscious, or unable to make decisions regarding LST. § 2133.03.	Yes. § 2133.14.
ОК	OKLA. STAT. ANN. tit. 63, §§ 3101.1– 3102.3 (West 2004 & Supp. 2011).	Advance Directive	P unable to make decisions about LST. § 3101.5.	Yes, but only to extent permitted by OK law. § 3101.14
OR	OR. REV. STAT. ANN. §§ 127.505– .660, 127.800–.897 (West 2003 & Supp. 2011).	Advance Directives for Health Care; Death with Dignity	P incapable of directing health care; determined by court or attending physician. §§ 127.505510.	Yes, subject to OR law. § 127.515.
PA	20 PA. CONS. STAT. ANN. §§ 5421–5471 (West 2005 & Supp. 2011).	Health Care	Living will operative when attending physician determines P incompetent and in end-stage or permanently unconscious. § 5443. DPAHC operative when attending physician determines P incompetent. § 5454.	Yes, unless inconsistent with PA law. §§ 5446, 5463–5464.
RI	R.I. GEN. LAWS §§ 23-4.10-1 to -12, 23-4.11-1 to -15 (2008).	Health Care Power of Attorney; Rights of the Terminally Ill	Declaration for LST operative when attending physician determines P in TC and unable to make medical decisions. § 23-4.11-3. DPAHC operative only when P unable to give informed consent. §§ 23-4.10-2.	Yes. §§ 23-4.10-11, -12.
sc	S.C. CODE ANN. §§ 44-77-10 to -160 (2002); S.C. CODE ANN. §§ 62-5-504 to -505 (2009 & Supp. 2010).	Death with Dignity; Health Care Power of Attorney	DPAHC effective when P mentally incompetent to make healthcare decision; determined by state code or physician determines P cannot make healthcare decisions; P's mental incompetence permanent or of extended nature. § 62-5-504.	Yes. § 44-77-65.
SD	S.D. CODIFIED LAWS §§ 34-12D-1 to -29 (2004 & Supp. 2011).	Living Wills	P in TC, not able to communicate medical care decisions, and death imminent, as determined by physician. § 34-12D-5.	Yes. § 34-12D-22.

WHO HAS A WILL TO LIVE?

TN	TENN. CODE ANN. §§ 32-11-101 to -113 (2007 & Supp. 2011); TENN. CODE ANN. §§ 34-6-201 to -218 (2007 & Supp. 2011); TENN. CODE ANN. §§ 68-11-1801 to -1815 (2011). TEX. HEALTH &	Right to Natural Death; Durable Power of Attorney for Health Care; Health Care Decisions	Physician determines P lacks capacity. § 68-11-1803. P determined incompetent by	Yes for living wills and DPAHC. § 32-11-111, -215. Yes, but expressly
1X	SAFETY CODE ANN. §§ 166.001–.166 (West 2010).	Directives	attending physician. § 166.152.	res, but expressly prohibits withdrawal of life support in manner not compliant with TX law. § 166.005.
UT	UTAH CODE ANN. §§ 75-2a-101 to -125 (LexisNexis 1993 & Supp. 2011).	Advance Health Care Directive	Physician, APRN, or PA finds P lacks decision making capacity, records finding, reasonable effort to communicate decision to P and surrogate. §§ 75-2a-104, -109.	Yes. § 75-2a-121.
VT	VT. STAT. ANN. tit. 18, §§ 9700–9720 (Supp. 2010).	Advance Directives for Health Care and Disposition of Remains	P lacks capacity; determined by P's physician. § 9706.	Yes, interpreted according to VT law. § 9716.
VA	VA. CODE ANN. §§ 54.1-2981 to -2993 (2009 & Supp. 2011).	Health Care Decisions	P incapable of making informed decision; determined by attending physician; must be reassessed every 180 days. Physician needs written certification from independent capacity reviewer unless P unconscious or unconsciousness due to trauma. § 54.1-2983.2.	Yes, executed based on VA law. § 54.1-2993.
WA	WASH. REV. CODE ANN. §§ 70.122.010925 (West 2011).	Natural Death	P permanently unconscious or in TC; determined by attending physician. § 70.122.030.	Yes, to extent permitted by WA law. § 70.122.030.
WV	W. VA. CODE ANN. §§ 16-30-1 to -25, 16-30C-1 to -16 (LexisNexis 2011).	Health Care Decisions; Do Not Resuscitate	P incapacitated; determined by physician or APNP; must inform P if conscious. § 16-30- 7. For do-not-resuscitate order, P must have incapacity. § 16- 30C-6.	Yes, for AD and DNR. § 16-30-21; § 16-30C-15.
WI	WIS. STAT. ANN. §§ 154.0129 (West 2006 & Supp. 2011); WIS. STAT. ANN. §§ 155.0180 (West 2006 & Supp. 2011).	Declarations to Physicians and Do-Not- Resuscitate Orders; Power of Attorney for Health Care	For living will, P in TC or PVS. § 154.03.	Yes. § 154.11.
WY	WYO. STAT. ANN. §§ 35-22-201 to -416 (2011).	Living Will	P lacks capacity; determined by primary or treating physician. § 35-22-403(d).	Likely yes (seeks uniform application among states enacting law). § 35-22- 416.

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