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ADVANCE MEDICAL DIRECTIVES IN THE ERA OF HEALTH CARE REFORM: WHO DECIDES?

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The alleged over-utilization of healthcare services at the end of life poses a wide range of ethical, empirical, and fiscal questions that have taken on greater urgency with the enactment of the Patient Protection and Affordable Care Act (ACA). Realized or not, the ACA's goal of "bending the cost curve"—that is, slowing the growth rate of healthcare spending—has inevitable consequences for the use of all forms of expensive medical interventions.[1] Likewise, well-founded or not, the controversy stirred by ACA opponents' allegations of "death panels" and "rationing" complicates what ought to be a broader societal discussion of how medical interventions are used to extend life, and in what context, and by whom, those decisions should be made.[2] Advance medical directives (AMDs)—whether based on living wills (LWs), the appointment of healthcare proxies or agents (HCAs),[3] or the emerging "paradigm" of Physician's Orders for Life-Sustaining Treatment (POLST)[4]—have long been advocated as a means to address these dilemmas.[5] But after more than three decades of experience with legislation and court decisions governing AMDs, it is appropriate to ask: Is this their proper purpose? And are they up to the task?

The hope that AMDs will rationalize end-of-life decision making, and perhaps help bend that cost curve, seems grounded more in optimism than in experience. Thirty years of research on advance directives reveals several obstacles to their effectiveness: most people do not execute AMDs; the prescribed legal forms (particularly LWs) are hard to understand and provide vague and unhelpful guidance; healthcare providers are often not aware an AMD exists for a particular patient; the "legal transaction" model underlying state laws on AMDs is ill-suited to the clinical setting and imposes needless execution requirements; and even HCAs are often unclear what to decide when their principal becomes incapacitated.[6] But little consensus exists on how to address these problems. Leon Kass and Eric Cohen criticize what they term "the gospel of the living will," not only pointing out these well-documented deficiencies in AMDs, but also questioning the presumption that ever-greater reliance on patient "autonomy" is the solution to the challenges of caring for those who have lost the capacity to decide for themselves.[7] To address the perceived deficiencies in LWs, other experts have proposed—and much legislation now reflects—a "menu" approach, in which patients state preferences regarding specific forms of treatment;[8] the POLST paradigm is built on this model.[9] This approach, in turn, has been criticized as "reactionary" and liable to frustrate the effectiveness of the advance directive as a tool to preserve the *prospective* decisional autonomy of a *patient* with present decision-making capacity.[10] It seems that all parties to this debate agree in principle that advance care *planning* is a laudable objective; they differ, however, on the utility of advance care *directives* in reaching that goal.

By considering the history of AMDs and the ethical issues posed by their use (or misuse), this article aims to provide clinicians and other healthcare providers (HCPs) with a framework for incorporating the use of AMDs that genuinely reflect the dignity and values of their patients into their practices more effectively. I contend that AMDs should not be oversold as a means to address broader concerns regarding the possible mis-utilization of medical care at the end of life;[11] indeed, the more this is done, the more likely the backlash that AMDs are intended to serve interests other than those of the dignity and values of individual patients. Rather than focusing on increasing the ubiquity (and legal enforceability) of AMDs, I suggest that we should focus first on the process of advance care planning in the clinical setting, and *then* assess what forms of AMDs may enhance that process. A more modest understanding of what AMDs can and cannot achieve may foster a more organic, patient-centered approach to these problems throughout medicine, thus reducing the conflicting demands that have fed this controversy over the past three decades, and are particularly acute today.

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The Development of AMDs: A Brief History

Living Wills: AMDs have been part of clinical practice for close to 40 years. California passed the first living will law, the Natural Death Act, in 1976, the same year that the New Jersey Supreme Court issued its decision in the case of Karen Quinlan, authorizing the withdrawal of a mechanical ventilator thought necessary to sustain her life.[12] The California law established the template for the first generation of LW laws: a standard, one-way directive (called a "Directive to Physicians") to refuse life-sustaining treatment in the event of terminal illness and loss of decision-making capacity.[13] The law's constrictive definition of life-sustaining treatment (LST) limited use of the directive to circumstances where death was imminent regardless of whether the LST was continued or not; this restricted the utility of the law and other first generation advance directive statutes.[14]

Common Law and Constitutional Law: More importantly from a legal perspective, early LWs also risked creating the impression that they provided the sole basis for decisions to withdraw LST. Court decisions in the 1980s clarified the issue, acknowledging that the common law protects the rights of patients to make medical treatment decisions and to have their wishes honored if they become incapacitated, with or without an AMD.[15] The United States Supreme Court, in the 1990 *Cruzan* decision, recognized the refusal of LST as a "liberty interest" protected under the Fourteenth Amendment to the Constitution—but a liberty interest subject to the State's interest in protecting life, which could be asserted by requiring clear and convincing evidence of a patient's prior wishes.[16] An AMD could certainly meet that evidentiary standard, but in practice courts often accepted far more informal prior oral statements as sufficient.[17] Most state advance directive laws now clarify that they do not preempt or impair existing rights and responsibilities under the common law, the Constitution, or other statutes regarding medical treatment decisions.[18]

Healthcare Powers of Attorney: By the time of the *Cruzan* decision, many states had recognized the deficiencies of the one-way LW provisions and enacted laws permitting individuals to execute a "durable power of attorney for health care," appointing a healthcare proxy or agent to make decisions for them if they became incapacitated.[19] The advantages of having an HCA are clear: the agent can interact with the treatment team to assess the specifics of the patient's condition and convey the patient's wishes with greater detail than can be conveyed through a one-size-fits-all LW. Some ethical issues remain, however: chiefly, is the agent's task simply to be a conduit for a patient's stated wishes, or also to express independent judgment about what would be in the patient's current best interests based on the particulars of the clinical situation? Though HCA laws do not constrain the decisions of agents in this regard, clinicians who interact with HCAs should be sensitive to this concern, just as they would be in the more common circumstance of interacting with a family member not formally appointed as an HCA who nonetheless acts *de facto* in that role.

> ***Yet, a comprehensive legislative scheme is no guarantee against intractable controversies at the bedside ... [Florida's] laws failed to prevent the bitter litigation over the treatment of Terri Schindler Schiavo.***

In 1991, New Jersey became the first state to adopt legislation merging the concepts of LW and HCA. Other states quickly followed.[20] Currently, all states and the District of Columbia have advance directive laws that, if not explicitly merging the concepts of LW and HCA, at least provide for both the appointment of an HCA and the execution of a narrative statement (and, in some states, a checklist) of treatment preferences.[21] Beyond this, the details of state legislation vary considerably, and attempts at uniformity have enjoyed at best a mixed rate of success.[22] Some states explicitly retain the LW concept by providing a standard statement or checklist of preferences along with the narrative option. For example, Connecticut law integrates provisions for a LW and appointment of an HCA, but each provision is optional; a patient does not have to do both. The LW portion in Connecticut specifies three forms of LST, with the option to reject or request each one: cardio-pulmonary respiration, artificial respiration, and nutrition and hydration by tube.[23] Massachusetts, on the other hand, has no LW provision, although appointment of an HCA may be accompanied by a narrative statement of preferences.[24] Meanwhile, several states retain the requirement that the advance directive follow a statutorily-prescribed form.[25] A minority of states permit execution of an oral advance directive, subject to varying requirements regarding witnesses and the medical condition of the patient.[26] States also differ in their treatment of specific forms of LST, particularly "artificial" nutrition and hydration, or tube feeding. Idaho, for example, states a default rule that tube feeding cannot be withdrawn if this would cause the death of the patient, but permits a patient to execute a directive to the contrary.[27] Other states, such as Colorado, provide two options: a patient can refuse all forms of LST, or refuse all LST except tube feeding.[28] Mississippi's law includes an optional set of "instructions for health care," as well as an option to choose medical treatment to prolong life "as long as possible *within the limits of generally-accepted health-care standards.*"[29] The highlighted language implicitly addresses the ethical problems posed in attempting to follow an advance directive to "do everything," without qualification, to sustain life. Other states have comparable provisions,[30] and virtually all states grant clinicians the right to refuse to

withdraw treatment based on conscience or other objections.[31] Yet, a comprehensive legislative scheme is no guarantee against intractable controversies at the bedside. Florida has long had one of the most comprehensive legislative schemes for AMDs and proxy decision-making, including virtually all the features discussed above.[32] Ironically, those laws failed to prevent the bitter litigation over the treatment of Terri Schindler Schiavo.[33]

ABBREVIATIONS:

- **AMD** (Advance Medical Directives);
- **HCA** (Healthcare Agent or Proxy);
- **LST** (Life-Sustaining Treatment);
- **LW** (Living Will);
- **POLST** (Physician Order for Life-Sustaining Treatment);
- **PSDA** (Patient Self-Determination Act)

Impact of AMD Laws: Despite this blanket of state laws, surveys consistently show that only a minority of patients who lack decision-making capacity have executed an AMD or appointed an HCA. Even where a patient has done so, obstacles remain: the written directive may not address the precise clinical dilemma at hand, the HCA may not be certain how to act, or the fact that an HCA or AMD exists may not be known to the treatment team. And in some cases, doctors who are aware of an HCA may even ignore it because they feel that more can be done to benefit the patient and prolong life.

Federal and state legislators have attempted for many years to bridge this gap. The Patient Self-Determination Act (PSDA),[34] enacted in 1990, required all Medicare and Medicaid provider organizations (hospitals, nursing homes, home health agencies, etc.) to provide written information to patients upon admission regarding their rights under state law to execute an AMD, to maintain written policies regarding AMDs, and to document in a patient's medical record if an AMD exists. The law also mandated states to provide a written description of their laws for providers to give to patients and called for the Department of Health and Human Services to undertake a public education campaign on AMDs. There is little evidence that the PSDA significantly increased the use of AMDs, however;[35] the required notification was subsumed in the volume of other paperwork typically accompanying a hospital admission, and the requirements upon governments were apparently met largely by doing the bureaucratic minimum.

More significant has been the enactment of laws in more than 40 states and the District of Columbia establishing a "default" list of surrogate decision-makers in the event of patient incapacity.[36] The laws vary considerably, with some (such as the District of Columbia) providing a rigid, hierarchical list, and others allowing greater flexibility. While the laws are intended to fill the gap when no AMD is available, they actually provide an additional incentive to create an AMD as well: the statutory list of surrogates may not reflect an individual's true wishes regarding who should make decisions for them. Clinicians can play an important role if, as part of their conversations with patients regarding advance care planning, they inform them that failure to appoint an HCA might mean the law will appoint one for them—perhaps a person who is not familiar with the patient's values and preferences.

More about advance care planning follows. But among the biggest issues facing physicians who wish to better serve their patients in this area are time and money. The initial House of Representatives version of the ACA included (in section 1233) a proposal to reimburse physicians for time spent with patients to discuss advance-care planning; it made such reimbursement contingent on physicians following a detailed "script" of the information that should be provided to patients. Critics of the ACA ominously castigated section 1233 as creating "death panels."[37] Even some who eschewed this rhetoric noted the potentially coercive aspect of the "script," which was apparently designed to compel the patient to consider the full range of potential medical treatment decisions and thus persuade the patient to make some form of advance directive.[38] The reimbursement provision was not included in the final version of the ACA, and attempts to resurrect a form of physician reimbursement for such conversations through regulation were eventually withdrawn by the Obama Administration.[39] It appears so far that this latest effort at the Federal level to create incentives for encouraging patients to execute AMDs will likely be no more effective than the PSDA of a quarter-century ago.

Beyond Traditional Advance Directives: The POLST Paradigm

The lack of adequate advance care planning, despite universal legislation on the subject, has been labeled an economic and public health "crisis" by some commentators,[40] and a predictable consequence of that very same legislative agenda by others.[41] One cannot doubt the persistence of those who seek to "lock in" a patient's wishes so that decisions about withdrawing life-sustaining treatment can be made more readily. (One recent proposal suggests further research into whether a "default" choice for comfort care over life-extending care might align AMDs better with a patient's true wishes and reduce the unnecessary use of medical resources.[42])

The latest effort to achieve this goal, the "Physician Order for Life-Sustaining Treatment" (POLST), has quietly gained traction in a large number of States, albeit under various names and with various forms of legislative support.[43]

The goal of POLST is straightforward and ambitious: to convert a patient's stated treatment preferences into an "immediately actionable medical order," memorialized in a standard, brightly-colored form that becomes part of the medical record for the patient.[44] POLST is designed to overcome at least two perceived gaps in existing laws on AMDs—immediacy and enforceability. The assumption driving POLST is that clinicians can, and indeed must, act promptly to comply with these "physician's orders" that are part of the patient's chart (or, in the developing future, electronic medical record). To this end, the standard POLST Form is simple and direct. It is a one-page, "multiple-choice" approach with three basic options: to accept or reject cardio-pulmonary resuscitation (or "Code"); to choose "comfort measures only," "limited additional interventions," or "full treatment"; and to request or refuse artificially administered nutrition and antibiotics.[45] Additional orders may be added to the standard form.

Much of the impetus for POLST lies in resolving the potential conflict for emergency medical providers who respond to calls involving a patient who has an AMD declining the use of CPR. In those circumstances, the values of immediacy and enforceability are paramount, so that emergency responders, in fulfilling their general obligation to employ CPR, do not override a patient's expressed wishes. But the aims of POLST are broader.[46] First developed in the 1990s at the Oregon Health & Sciences University (OHSU), the "POLST Paradigm" remains effectively under OHSU's purview. OHSU's POLST Program certifies as "endorsed" POLST initiatives State and local programs that meet defined standards for supervision, education and training, and ongoing evaluation, as well adopting a compliant POLST form. As of June 2013, 14 States had "endorsed" POLST programs, and 29 were classified as "developing."

POLST's proponents emphasize that completion of the form should be the end-point of a process of advance care planning that begins in the clinical setting, ideally any time that a patient is expected to live a year or less. POLST criteria stipulate that patient participation must be voluntary, even under provisions that require patients to be informed of the option to participate. POLST forms are also to be reviewed and updated if there is a substantial change in a patient's health status, if a patient's treatment preferences change, or if the patient is transferred from one treatment setting or care level to another.[47] While compatible with existing AMD schemes, POLST aims to shift the locus of advance care planning to the clinical setting and to ensure that the outcome is clearly recorded in a manner that HCPs can understand and follow. Optional POLST registries, available in a handful of States, allow patients to ensure that their POLST form is recorded electronically and thus available if the printed form cannot be located by healthcare providers.[48]

Whether the POLST Paradigm will succeed in making advance care planning

more common and patient wishes more closely adhered to where other initiatives have failed remains an open question. Much depends on whether close consultation with a physician before a form is executed, which is an assumption of the Paradigm, occurs effectively in the clinical setting. It may be naive to assume, for example, that the completion of POLST forms will be any more consultative or informative (from the patient's perspective) than the oft-criticized process for obtaining informed consent. The five principal criticisms directed at living wills by Fagerlin and Schneider suggest five pertinent questions for the POLST Paradigm: **(1)** Will enough people decide to execute the forms, and will their reasons for declining to do so be respected? **(2)** Will the creation of POLST forms comply with standards for informed consent, including being current and relevant to the treatment decisions in question? **(3)** Does the brief POLST document genuinely reflect accurate and effective treatment preferences? **(4)** Will POLST forms be available when treatment decisions must be made, as they are designed to be? And, **(5)** will POLST forms guide or override the input of a designated HCA regarding treatment decisions?

Working with Advance Directives: Clinical Considerations

As the foregoing discussion indicates, clinicians face a bewildering array of patient needs, societal expectations, and legal standards in the area of advance care planning. Few dispute that modern medicine has fallen short in bridging the gap between the vast array of treatments and technology that can be used to preserve life and the limited knowledge most patients (and families) possess about the efficaciousness of such treatments and whether they would be consonant with a patient's values and desires. For all the good intentions behind them, state statutes regarding AMDs offer limited help in bridging this gap, and may in fact have been counterproductive.[49] It comes as no surprise, therefore, that years of legislative enactments have done little more than codify the pre-existing, fundamental principle that patients possess the rights to state their preferences for medical treatment and to have those preferences honored.

But reinforcement of that principle is not a bad place to begin the discussion of how clinicians can better guide their patients in the process of advance care planning. The temptation, fed by years of legislation and celebrated court cases, is to see end-of-life care as a legal dilemma, as opposed to a challenge rooted primarily in the ethics of medicine. The widespread image of medicine thwarting the (expressed or inchoate) desire of patients to be free of LST ignores the complexities of clinical practice as well as the tentative nature of many expressions of patient preference. On the other hand, such images often fuel the demand for further laws on AMDs when, in fact, long-established principles of the common law provide ample space for HCPs and patients to engage in advance planning discussions that will result, as one proponent says of AMDs, in "sufficient guidance to those responsible for the patient's care."[50] In short, legal officiousness should not interfere with, and surely will not improve, the practice of good, patient-centered medicine as life draws to a close.

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Guarding against such officiousness requires familiarity with the law and particularly with the specific forms of advance directives, including those associated with the POLST paradigm, in the jurisdictions where a clinician practices. Should a physician anticipate that a patient's illness may result in incapacity to make treatment decisions, the physician ought to broach the subject of advance care planning, especially to determine whom the patient would want to make treatment decisions if incapacity occurs. From this could follow discussion of specific treatment options, entry of DNR orders, and related decisions. Without providing legal advice, physicians and other HCPs can then inform patients that legal avenues exist to put down their preferences in writing, under laws that will help those preferences to be enforced. If a patient is reluctant to execute an AMD under state law, the basis for that reluctance can be explored, but the ultimate decision is the patient's. The physician should assure such patients that they will act, even absent an AMD, to follow the patients' expressed wishes to the greatest extent possible and consistent with sound medical practice.

Commentators have debated whether ethical principles governing informed consent, particularly regarding specific treatment options, should be followed in the process of executing AMDs.[51] One modern principle of informed consent, however, should be non-negotiable: just as informed consent to a particular medical procedure is a process, not an event, ascertaining a patient's wishes regarding appointment of a HCA or other AMD should not be an abrupt or reflexive undertaking. In particular, when advising clients for whom terminal illness and/or incapacity is not merely a speculative event, physicians should reassure those persons that the choice between treatment designed to extend life and palliative care to provide comfort is not mutually exclusive (allowing, of course, for any physical burdens or pain associated with continued LST). Physicians can advise patients that there is a continuum of care that can (and will) be adjusted to meet the patient's goals for treatment.

The Distinct Roles of Physicians & Attorneys

Clinicians should not attempt to be lawyers, but they need to be familiar with the basic requirements of their own

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state's laws regarding AMDs. In those states that permit execution of an oral AMD, physicians should provide that option (with knowledge of any requirements for witnessing, etc.) in the discussion of advance care planning. Clinicians also need to be aware of any legal requirements for certifying that a patient has lost decision-making capacity, thus triggering the authority of a HCA to make treatment decisions. Most state laws require certification by a second physician of the loss of capacity; some even require the involvement of a psychiatrist, psychologist, or other specialist with expertise in making such determinations. Finally, physicians should be aware of their rights and obligations to refuse to participate in the withdrawal or provision of medical treatment on grounds that such actions are ethically inappropriate.

clients to consult a physician with any questions regarding the medical impact of decisions and treatment preferences stated in an AMD and, if the client chooses to do so, forego final execution of such documents until that consultation has taken place. Similarly, physicians, HCPs, and healthcare institutions ought to be aware that patients may have executed an AMD with their lawyers and inquire whether such documents exist. Both physicians and attorneys should be aware that the more remote a statement of treatment preferences is, the less reliable it may be as an accurate predictor of what the patient would want in the present. Just as "old" testamentary wills should be accounted for and revisited, so too with "old" AMDs.

For attorneys in particular, it is not sufficient to be knowledgeable regarding specific state legislation on AMDs.[52] To

> ***Decades of experience demonstrate that AMDs are no panacea for the ethical dilemmas posed by end-of-life decision-making.***

Just as clinicians should not play lawyer, attorneys should not be placed in the position of speculating regarding the potential outcome of decisions set forth in a statutorily-prescribed AMD form. This brings up an unfortunate reality regarding AMDs: many people will first engage in discussion of such documents, and thus begin the process of advance care planning, when preparing their wills and other estate-related documents. In other words, in the office of their attorney, not their doctor. Lawyers (unlike, typically, physicians) are reimbursed through client fee for engaging in these discussions and preparing the necessary documents, and so have an incentive—and likely an ethical obligation—to advise their clients on the law governing AMDs. These discussions and decisions may take place years or decades before the anticipated onset of terminal illness (consider the young couple planning their estate after birth of a first child). Wise attorneys will advise meet the goals of advance care *planning*, any statutorily-prescribed form of AMD (including one with checklists for various treatment options) should be stringently examined before execution to determine if it meets the standards of disclosure sufficient for a client/patient to understand the nature of what the directive purports to decide. Ethically-adequate informed consent requires capacity, autonomy (freedom from coercion, duress, or manipulation), the disclosure of all relevant information (admittedly difficult when giving or declining consent to future treatment), and comprehension.[53] The debate on the *extent* and *detail* to which these principles should be applied to the formulation of advance directives may not yet be resolved, but there should be no dispute that a fundamental level of capacity, autonomy, disclosure, and comprehension should be assured before an AMD is executed.[54] Conversely, simply because an AMD has been executed does not necessarily mean that the patient received an adequate disclosure of information or comprehended what information he or she received.[55]

Finally, physicians and attorneys should both be aware that a validly-executed AMD is of no use if it is not available when the patient/client becomes incapacitated. The existence of an AMD may be noted in a medical chart even without following the full POLST paradigm, and an attorney should advise clients that, unlike a testamentary will, an AMD must be quickly accessible as well as securely filed.

Conclusion: Kass and Cohen aptly express the skeptical view toward AMDs, which runs counter to the more prevalent, favorable view of such instruments:

> If living wills promote a deeper understanding of what it means to age well and care well, then we are all for them. If they help preserve even a dose of loving humanity in the face of the "machinery of the modern hospital," then we endorse them. But the evidence suggests that living wills have largely failed to meet these noble ends, and that no legal instrument can liberate us from the human dilemmas of learning how to put ourselves in the hands of caregivers, and how to care for those who put their trust in us.[56]

Decades of experience demonstrate that AMDs are no panacea for the ethical dilemmas posed by end-of-life decision-making. Where available and reliable, they should be given their proper legal effect; to do otherwise is to erode the dignity of the patient. Yet, their inherent limitations should be more widely acknowledged, and, most important, the execution of an AMD should not be a substitute for proper advance care planning that arises primarily from the relationship between the patient and the physician or other HCP. In the long run, changing the focus in advance care planning from a "legal transaction" approach governed by a web of complex state statutes to one grounded

in the physician-patient relationship, communication, and consideration of the full context of the patient's condition—not merely the fact of terminal or debilitating illness—should be the goal. Approaches such as those advocated by the "Five Wishes" campaign offer an alternative to the "legal transaction" paradigm.[57] Those engaged in the quotidian task of advising and counseling their patients and clients have a pivotal role to play in lowering expectations regarding the efficacy of advance directives in solving broader healthcare issues, while ensuring that the directives executed by those patients and clients are reliable and effective statements of their genuine wishes for end of life care.

1 Steven A. Schroeder, "Personal Reflections on the High Cost of American Medical Care: Many Causes but Few Politically Sustainable Solutions," *Archives of Internal Medicine* 171, no. 8 (April 25, 2011): 722.

2 Mary E. Tinetti, "The Retreat from Advanced Care Planning," *Journal of the American Medical Association* 307, no. 9 (March 7, 2012): 915.

3 Charles P. Sabatino, "Advance Directives and Advance Care Planning: Legal and Policy Issues," U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy (October 2007), http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.pdf

4 Thaddeus Mason Pope and Melinda Hexum, "Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment," *Journal of Clinical Ethics* 23, no. 4 (2012): 353.

5 Dan K. Morhaim and Keshia M. Pollack, "End-of-Life Care Issues: A Personal, Economic, Public Policy and Public Health Crisis," *American Journal of Public Health* 103, no. 8 (June 2013).

6 Sabatino, "Advance Directives," 18-19; Lesley S. Castillo et al., "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care," *Annals of Internal Medicine* 154 (January 18, 2011): 121.

7 Eric Cohen and Leon R. Kass, "Cast Me Not Off in Old Age," *Commentary* 121, no. 1 (January 2006): 34-36.

8 Linda Emanuel et al., "Advance Directives for Medical Care: A Case for Greater Use," *New England Journal of Medicine* 324, no. 13 (March 28, 1991): 889; Linda Emanuel and Ezekiel Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *Journal of the American Medical Association* 261, no. 22 (June 9, 1989): 3288.

9 Pope and Hexum, "Legal Briefing," 353.

10 Robert S. Olick, *Taking Advance Directives Seriously* (Washington D.C.: Georgetown University Press, 2004), 80-82, 98-114.

11 Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (March-April, 2004): 30.

12 In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976).

13 See Alan D. Lieberson, *Advance Medical Directives* (Deerfield, IL: Clark Boardman Callaghan, 1992), 44-53.

14 Lieberson, *Advance Medical Directives*, 46.

15 See, e.g., In re Storar, 52 N.Y. 2d 363 (1981); In re O'Connor, 72 N.Y.2d 517 (1988); Estate of Longeway, 133 Ill2d 33 (1989).

16 *Cruzan v. Director,* Missouri Department of Health, 497 U.S. 261 (1990).

17 In *Cruzan*, for example, the case was eventually remanded to a Missouri probate court, which accepted as clear and convincing evidence of Nancy Cruzan's wishes the testimony of friends regarding a casual conversation about the use of LST on disabled children they cared for as teacher's aides. *Cruzan v. Mouton*, Estate No. CV384-9P (Circuit Ct., Jasper County, Mo., Probate Div.) (December 14, 1990). For discussion, see Edward R. Grant and Cathleen A. Cleaver, "A Line Less Reasonable: *Cruzan* and the Looming Debate over Active Euthanasia," *Maryland Journal of Contemporary Legal Issues* 2, no. 99, (1991) 147-153.

18 Sabatino, "Advance Directives," 2-3.

19 Lieberson, *Advance Medical Directives*, 278-322.

20 Sabatino, "Advance Directives," 12-13.

21 The National Hospice and Palliative Care Organization maintains an electronic library of all state advance directive forms as a resource for patients, families, and caregivers. http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289 (accessed September 3, 2013).

22 An example is the Uniform Health-Care Decisions Act (UHCDA), promulgated in 1993 by the National Conference of Commissioners on Uniform State Laws (ULC), a nonpartisan organization that promulgates proposed model legislation on a wide variety of legal issues. The ULC had previously issued the Uniform Rights of the Terminally Ill Act (1985), an effort to harmonize existing LW legislation. The problem, as noted by one of the authors of the UHCDA, is that states had already enacted their own LW and other advance directive legislation, and had little incentive to harmonize their laws with those of other states. David M. English, "The Uniform Health-Care Decisions Act and Its Progress in the States," *Probate and Property*, (May/June, 2001), http://www.americanbar.org/publications/probate_property_magazine_home/rppt_publications_magazine_2001_01mj_01mjenglish.html (accessed September 3, 2013).

23 Conn. Gen. Stat. §§ 19a-570. 575-577.

24 Mass. Gen. Law 201D §§ 1, 4.

25 See, e.g., Ore. Rev. Stat § 127.515(3).

26 Castillo, "Lost in Translation," 121, 123-124; See, e.g., Va. Code § 54.1-2983.

27 Id. Code § 39-4510.

28 Co. Rev. Stat. §§ 15-18-101, 104.

29 Miss. Code Ann. §§ 41-41-209.

30 The Virginia statute, for example, specifically provides "[n]othing in this article shall be construed to require a physician to prescribe or render health care to a patient that the physician determines to be medically or ethically inappropriate." Va. Code § 54.1-2990. A physician who objects to a request for particular treatment must inform the patient or appointed HCA of the objection and, if it cannot be resolved, make "reasonable effort" to transfer the patient to a physician who will comply. *Ibid*. See also Md. Code Health Gen. § 5-611; Fla. Stat. § 765.1108.

31 Castillo, "Lost in Translation," 125.

32 Fla. Stat. Ann. §§ 765.301 - 765.309.

33 The Ethics Program at the University of Miami maintains a useful compendium of materials regarding the Schiavo case, accessible at http://www.miami.edu/index.php/ethics/projects/schiavo (accessed September 5, 2013). The Supreme Court of Florida also maintains a website with links to all of its opinions in the matter, accessible at http://www.floridasupremecourt.org/pub_info/schiavo/index.shtml (accessed September 5, 2013).

34 42 U.S.C. § 1395cc(f)(1), (2).

35 Fagerlin and Schneider, "Enough," 32.

36 Sabatino, "Advance Directives," 11; American Bar Association, Commission on Law and Aging, "Default Surrogate Consent Statutes," (November 2009), http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/famcon_2009.authcheckdam.pdf (accessed September 3, 2013).

37 The charge was at least a malapropism, perhaps borne of confusion between section 1233's provisions for advance care planning and other provisions of the ACA, which survived to final enactment, creating the Independent Payment Advisory Board (IPAB). IPAB, a 15-member commission appointed by the President in consultation with Congressional leadership, is mandated to achieve cost savings in the Medicare program should the rate of growth in Medicare spending exceed specified limits. Despite provisions in the ACA stating that spending cuts should not affect Medicare coverage or the quality of care, critics have alleged that IPAB's decisions will result in rationing of health care. See David B. Rivkin, Jr., and Elizabeth P. Foley, "An ObamaCare Board Answerable to No One," *Wall Street Journal*, June 20, 2013, A21; Howard Dean, "The Affordable Care Act's Rate-Setting Won't Work," *Wall Street Journal*, July 29, 2013, A13; Peter R. Orszag, "The Critics Are Wrong about IPAB," *The Health Care Blog*, July 31, 2013, http://thehealthcareblog.com/blog/2013/07/31/the-critics-are-wrong-about-ipab/ (accessed September 3, 2013).

38 See Charles Lane, "Undue Influence," *Washington Post*, Aug. 8, 2009, http://articles.washingtonpost.com/2009-08-08/opinions/36869317_1_advance-directives-end-of-life-new-patients (accessed September 3, 2013).

39 Tinetti, "The Retreat from Advanced Care Planning," 2.

40 Morhaim and Pollock, "End-of-Life Care Issues," 5.

41 Fagerlin and Schneider, "Enough," 11.

42 Scott D. Halpern et al., "Default Options In Advance Care Directives Influence How Patients Set Goals for End-Of-Life Care," *Health Affairs* 32, (Feb. 2013): 408.

43 Pope and Hexum, "Legal Briefing," 343.

44 Susan E. Hickman et al., "The POLST (Physician Order for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation," *Journal of Law, Medicine & Ethics* 36, no. 1 (2008) 119.

45 This is based on the POLST form adopted by the California Emergency Medical Services Authority. http://www.emsa.ca.gov/pubs/pdf/

ApprovedPOLSTForm.pdf

46 Most states addressed this conflict in the 1990s through legislation or regulatory protocols permitted execution of and adherence to out-of-hospital do not resuscitate orders. Sabatino, "Advance Directives," 10.

47 Pope and Hexum, "Legal Briefing," 361.

48 *Ibid*., 363.

49 Bernard Lo and Robert Steinbrook contend that the legal formalities associated with AMDs place burdens on patients and physicians that complicate the process of advance care planning. See B. Lo and R. Steinbrook, "Resuscitating Advance Directives," *Archive of Internal Medicine* 164, no. 14 (July 26, 2004): 1501, 1502-04. See also Castillo, "Lost in Translation," 121-126.

50 Olick, *Taking Advance Directives Seriously*, 81.

51 Ibid., 104-108; Cf. Emanuel & Emanuel, "The Medical Directive," 3288-3293.

52 Attorneys in particular should be fully-versed in the common-law and related judicial pronouncements in their states (and in those in which their clients reside) as they may affect the ability to draft enforceable advance directives outside the statutorily-prescribed AMD forms.

53 Edmund D. Pellegrino and Daniel P. Sulmasy, "Medical Ethics," Section 2.3 in *Oxford Textbook of Medicine*, 4th ed., ed. David A. Warrell et al. (New York: Oxford University Press, 2003).

54 Robert Olick, a critic of applying informed consent standards designed for contemporaneous medical treatment decisions to the execution of AMDs, nonetheless acknowledges "the informed consent model is an important yardstick for much-needed efforts to improve the use of advance directives and to make advance care planning a standard component of the physician-patient relationship." Olick, *Taking Advance Directives Seriously*, 107.

55 Olick, for example, concedes that a "nonautonomous" directive may be overridden in favor of an assessment of a patient's current best interests. *Ibid*., 80-82, 113.

56 Eric Cohen and Leon Kass, "Old Age," *Commentary* 121, no. 4 (April 2006): 16.

57 The Five Wishes campaign is the product of Aging with Dignity, a non-profit founded by a former legal counsel to Mother Teresa of Calcutta. www.agingwithdignity.org