

## The Evolution of Health Care Advance Planning Law and Policy

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**Context:** The legal tools of health care advance planning have substantially changed since their emergence in the mid-1970s. Thirty years of policy development, primarily at the state legislative level addressing surrogate decision making and advance directives, have resulted in a disjointed policy landscape, yet with important points of convergence evolving over time. An understanding of the evolution of advance care planning policy has important implications for policy at both the state and federal levels.

**Methods:** This article is a longitudinal statutory and literature review of health care advance planning from its origins to the present.

**Findings:** While considerable variability across the states still remains, changes in law and policy over time suggest a gradual paradigm shift from what is described as a “legal transactional approach” to a “communications approach,” the most recent extension of which is the emergence of Physician Orders for Life-Sustaining Treatment, or POLST. The communications approach helps translate patients’ goals into visible and portable medical orders.

**Conclusions:** States are likely to continue gradually moving away from a legal transactional mode of advance planning toward a communications model, albeit with challenges to authentic and reliable communication that accurately translates patients’ wishes into the care they receive. In the meantime, the states and their health care institutions will continue to serve as the primary laboratory for advance care planning policy and practice.

**Keywords:** advance care planning, advance directives, living wills, public policy.

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SINCE THE MID-1970S, HEALTH CARE ADVANCE DIRECTIVES HAVE been promoted as the primary legal tool to communicate formally one's health care wishes regarding end-of-life care and, presumably, to enhance the likelihood that one's wishes are followed by health care professionals. These documents spell out one's health care goals and instructions and appoint an agent or proxy decision maker in the event of incapacity. Whether advance directives laws offer a viable approach to that goal, however, is still very much an open question. This article provides an overview of the evolving legal landscape of end-of-life decision making generally, and advance directives specifically, and highlights a fundamental shift in that landscape. First I review the statutory history of advance directives and then describe a paradigm shift in state law away from standardized, formal legal documents to a communication-oriented approach to advance care planning. Then I introduce Physician Orders for Life-Sustaining Treatment, the next step in the evolution of advance care planning. Finally, I discuss the lessons of this evolution for both state and federal policymakers.

## A Statutory History

The first advance directive was proposed by the Euthanasia Society of America in 1967 (Glick 1991). Luis Kutner, a human-rights lawyer from Chicago who represented the society, described this concept in a 1969 article. He began with the common law and constitutional law premises that "the law provides that a patient may not be subjected to treatment without his consent" (Kutner 1969, 550). The challenge was what to do about patients who no longer were capable of making health care decisions. He suggested that the individual should indicate in writing ahead of time the extent to which he or she would consent to treatment. He referred to the document as a "living will," "a declaration determining the termination of life," or a "testament permitting death," among other names (Kutner 1969, 551).

Kutner also compared the living will with "a revocable or conditional trust with the patient's body as the res, the patient as the beneficiary and grantor, and the doctor and hospital as the trustees" (1969, 551). As with any trust instrument, the document sets forth the terms for managing the res, which, in the context of medical care, means the extent to which the health care providers should undertake treatment. Kutner's testamentary

and trust paradigms are characteristic of the legalistic paradigm that the states initially embraced in their advance directive legislation.

Legislative permutations of health care advance directives have evolved dramatically, albeit incrementally, from this legal construct, starting with California's adoption of the first living will statute in 1976 that created its Directive to Physicians, more popularly called a *living will*. The living will model sought to offer something inviting to both individuals and physicians. To individuals, it offered a standardized tool to express their wishes about life-sustaining treatment—usually to withhold or withdraw it—in the event of a terminal condition or permanent unconsciousness. To physicians, the living will offered statutory immunity if they complied with the patient's wishes in good faith.

One might ask today, more than thirty years later, why physicians would need the carrot of immunity to do what the underlying law already presumably required, that is, to respect their patients' wishes. The answer is that technological developments in medicine during the 1960s and 1970s thrust medicine into a new world where for the first time, it often became difficult to distinguish saving life from prolonging suffering and death (Colby 2006). A *Time* magazine (1975) review of the then pending Karen Ann Quinlan trial in New Jersey in 1975, captured the tenor of the time:

Many doctors, after all, are taught to regard death as an enemy and to do all they can to defeat it—or at least to keep it at bay for a while. Many regard “pulling the plug” as an act akin to euthanasia, which is forbidden by both law and the medical code.

The *Time* article ended with broader policy concerns that still resonate in today's debates about terminating treatment:

For although the Quinlan case concerns mainly the maintenance of life by artificial means, it could, if carried to its logical conclusion, be applied in state hospitals, institutions for the mentally retarded and for the elderly . . . [and] could prompt new suits by parents seeking to end the agony of incurably afflicted children, or by children seeking to shorten the suffering of aged and terminally ill parents.

It was concerns like these that resulted in a legal model of advance care planning that focused on conventional legal formalities or procedural protections intended to protect vulnerable populations from harm,

specifically the premature termination of life due to the lack of understanding of, or diminished capacity of, or undue influence on, the signer of the living will.

The number of living will laws snowballed during the next ten years, so that by the end of 1986, forty-one states had adopted them (Glick 1991, 289). But the shortcomings of living wills gradually became apparent to policymakers and the public, especially with respect to the narrow range of decisions to which the laws applied. In response, policymakers turned to validating and reshaping the use of another legal document: the durable power of attorney (Sabatino 1991/1992).

Powers of attorney existed in the common law as a tool by which a principal could empower an agent to act on the principal's behalf. They were originally used to delegate authority over property matters. Under the common law, a power of attorney was revoked as a matter of law by the incapacity of the principal. Thus, the common law power had no utility as a planning tool for incapacity. In 1954, Virginia enacted the first "durable" power of attorney statute (in this case, for property matters) that allowed an agent to continue to act as empowered by a power of attorney even after the principal lost capacity (see Virginia Code §11-9.1). Other states quickly followed suit (Dessin 1996).

The use of powers of attorney as a health care decision making tool has obvious advantages over the living will. Indeed, as far back as 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research favored their use for health care decision making, but the commission also voiced a concern for the potential of abuse inherent in conventional powers of attorney used for health care decision making:

These statutes do not have rigorous procedures because they were enacted primarily to avoid the expense of full guardianship or conservatorship proceedings when dealing with small property interests. Adapting them to the context of health care may require that greater procedural safeguards be provided: precisely which safeguards are needed might best be determined after more experience has been acquired. (President's Commission 1983, 147)

To address these concerns while encouraging the use of powers of attorney for health care, the states began crafting special durable powers of attorney for health care statutes or, alternatively, adding

proxy provisions to their living will statute. This wave of legislation took place roughly from the mid-1980s to the mid-1990s, with California again leading the pack with its 1983 law.<sup>1</sup> By the end of 1988, only twelve states had such statutes, but by the end of 1997, every state had enacted some version of a health care power of attorney statute (Commission on Law and Aging 1998).

A third wave of legislation began in the early 1990s, triggered by the growing awareness of unwanted resuscitations of terminally ill patients living at home or in a hospice, occurring when an expected medical crisis arose and someone on the scene called 911. Without an out-of-hospital do-not-resuscitate (DNR) protocol, emergency medical services personnel are obligated to do everything possible to resuscitate a patient whose heart or breathing has stopped. Moreover, an advance directive normally does not trump that obligation (Iserson 1991; Koenig and Tamkin 1993). To address these unwanted medical encounters, the states began enacting legislation or regulations in the early 1990s to permit seriously ill persons in the community to avoid unwanted resuscitation through the use of out-of-hospital DNR orders (sometimes called do-not-attempt-resuscitation orders, comfort care orders, or CPR directives). These protocols usually required the DNR order to be signed by both the physician and the patient (with many states permitting a surrogate to sign) and the use of a specially designed identification bracelet or form to be kept on or near the patient. By the end of 1999, forty-two states had statewide protocols in place, usually created by legislation (Sabatino 1999).

A fourth wave of legislation more accurately resembles a slowly rising tide rather than a wave. This legislation addresses the other side of the coin—how decisions are to be made in the absence of an advance directive—and its origins date back to the 1960s. Now, as in the 1960s, most decisions relating to end-of-life care for persons lacking decisional capacity are made without the guidance or authority of a health care advance directive. Historically, state law did not identify who, in the absence of an appointed agent or guardian, was authorized to make decisions in these instances.

Default surrogate consent or family consent laws provide an answer to that question. These exist today in forty-four states and the District of Columbia, although they vary significantly in breadth and depth and legislative origin (Commission on Law and Aging 2009a). Some apply only to particular decisions such as resuscitation or medical research

consent. All create a list of permissible surrogates, usually starting with spouse and a next-of-kin priority list. Some limit surrogates to fairly close relatives. Iowa, for example (see Iowa Code Ann. §144A.7), authorizes one's spouse, followed by an adult child, a parent, and an adult sibling. Others extend this list to any adult relative, with no limitation of degree. A growing number of states, nearly half today, include "close friend" or its equivalent in the list of permissible surrogates, though usually at or near the end of the order of priority. Arizona, in addition, includes the "patient's domestic partner" as an authorized surrogate for some health decisions (see Ariz. Rev. Stat. §36-3231), although in other states, the definition of a close friend may be broad enough to encompass a domestic partner.<sup>2</sup>

These laws also vary significantly in the scope of authority granted to surrogates and in the procedural formalities required in the decision making process. Most also fall short of a solution for those who lack any close family or friends, the so-called unbefriended patient (Karp and Wood 2003). But at least they provide a clear hierarchy of decision making authority in the more conventional family constellations.

The fifth, and perhaps most important, wave of legislation began when the separate health care decision acts that the states had already enacted were merged. This was driven in part by the growing awareness of the public's lack of understanding of these documents' legal complexities, plus their persistent underuse. Most estimates of completion rates by adults of all ages in the early 1990s hovered around 20 percent or less (Larson and Eaton 1997, 276).

New Jersey enacted the first combined statute in 1991, merging the living will (called an "instruction directive") and the durable power of attorney for health care (called "a proxy directive") into a single "advance directive for health care" (see N.J. Stat. Ann. §26:2H-53 to -81). By the beginning of 2000, sixteen states had comprehensive or combined advance directive statutes, which at a minimum combined living wills and proxies in the same law (Commission on Law and Aging 2000). Today, that number has inched up to twenty-five (Commission on Law and Aging 2009b). The more comprehensive of these statutes also authorize default surrogate decision makers in the absence of an advance directive and provide the option of including organ donation instructions in one's advance directive.

The primary model for a flexible combined advance directive and default surrogate law has been the Uniform Health-Care Decisions Act

(Uniform Law Commission 1993). The Uniform Act was promulgated as a national model by the National Conference of Commissioners on Uniform State Laws in 1993 and establishes very simple rules for recognizing almost any kind of written or oral statement as an advance directive. Although even unwitnessed documents are valid under the Uniform Act, those states that have adopted the act have almost always added more to its baseline requirements. Indeed, all states adopting the act have mandated a witnessing requirement. The Uniform Act provides an optional sample form with options to give instructions about one's care, appoint an agent, make an organ or tissue donation, and name a primary physician. The act also recognizes default surrogates in the absence of an advance directive.

The federal legislative role in this evolution has been minimal. The primary congressional foray into the subject is the Patient Self-Determination Act, enacted as part of the Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508. This act was a fairly modest amendment to federal Medicare and Medicaid law, intended to encourage adults to think about and plan for health care decisions. At its heart, it is an information and education mandate, as it does not create or change any substantive right to health care decision making. Rather, it requires all Medicare and Medicaid provider organizations (specifically, hospitals, skilled nursing facilities, home health agencies, hospices, and prepaid health care organizations) to do five things:

1. Provide written information to patients concerning their right under state law to make decisions about their medical care and the right to formulate advance directives.
2. Maintain written policies and procedures regarding advance directives and make them available to patients upon request.
3. Document whether or not the patient has executed an advance directive.
4. Comply with the requirements of state law respecting advance directives.
5. Educate staff and community on advance directives. (Sabatino 1991/1992)

In 2008, Congress added "end-of-life planning" to the one-time only, initial preventive physical examination (sometimes called the "welcome to Medicare exam") available to newly enrolled Medicare beneficiaries

(see 42 U.S. Code §1395(x)(v)(3)). In 2009, Congress fiercely debated major health reform proposals, one of which would provide Medicare coverage of voluntary advance care planning consultations, but such a provision failed to make it into the final version of health reform.

In regard to the substantive elements of health care decision making, federal law has generally deferred to state substantive law, including the selection and authority of appointed agents and default surrogates. There is one exception, however. In 1996, Congress enacted a federal advance directive option solely for military personnel that explicitly preempts state law (see 10 U.S. Code §1044c). This federal incursion into state authority is limited and justifiable by the needs of military service, so it does not signal a trend toward the federalization of advance planning law.

## The Paradigm Shift in State Law

For most of the history just described, advance directive laws predominantly emphasized standardized legal forms characterized by mandatory formalities and restrictions, with procedural requirements and limitations intended to serve as protections against abuse and error. This approach could be characterized as a “legal transactional approach.” Over the past two decades, this approach has been slowly and incrementally moving toward an approach that more strongly acknowledges an ongoing and flexible process of communication. This newer model could be described as a “communications approach.”

### *The Legal Transactional Approach*

A legal transactional framework focuses on the formal steps of creating and implementing the legal tools to direct or delegate health care decisions in advance of decisional incapacity. Accordingly, the creation of an advance directive is treated much like a conventional conveyance of interest in property or a contract that establishes important rights and obligations. The validity of the transaction focuses on required legal formalities and standardization of the process.

The completed document was expected to promote compliance with the preferred legal standard for decision making, referred to as the



“substituted judgment” standard. In simplest terms, the substituted judgment standard requires a surrogate to make a treatment decision in the manner in which the patient would have decided if the patient could speak for himself or herself. It requires sufficient evidence of the patient’s preferences. The advance directive was to be the gold standard for ascertaining the patient’s treatment wishes. For reasons detailed later, this approach turned out to be naïve at best. When it is not possible to ascertain the patient’s preferences, the law imposes a so-called best-interests standard of decision making, requiring the surrogate to choose the course of action that would promote the patient’s interests as they would probably be determined by a reasonable person in the patient’s circumstances. Ultimately, these distinctions in surrogate decision making standards have proved to be difficult to parse and also to implement in both the legal and clinical worlds (Meisel and Cerminara 2010). Nevertheless, formal advance directives have become public policy’s choice for championing patient autonomy in the face of incapacity.

Legal formalities are intended to impress on the parties the seriousness of the transaction and its potential consequences. And because this is a legal tool that often will be signed and used without the advice of legal counsel, detailed standardized formalities are relied on to ensure the user’s voluntary, knowing, and competent execution of the transaction, as well as to ensure its recognition and compliance by health care providers.

States have required several kinds of legal formalities for executing advance directives. The following examples represent the state of the law in 2007:

1. *Standardized statutory forms.* Although in most states, these are provided as optional models, they sometimes are regarded as the only safe option to use and, consequently, may become virtually mandatory. This is especially true in thirteen states that require advance directives to be “substantially” in the form contained in the statute.<sup>3</sup>
2. *Required disclosures or warnings.* Eight states require specific written disclosures in the form to serve as a notice to persons executing health care powers of attorney—a kind of Miranda warning for users.<sup>4</sup> In six of these states, this requirement is part of the mandatory forms just noted, although two—Ohio and Wisconsin—apply the requirement to any preprinted form distributed in the state.

3. *Prescribed phrases for authorizing certain wishes.* A number of states require that the directive expressly address certain matters, such as nutrition and hydration, with specificity if it is the individual's intent to authorize withdrawal. Furthermore, the specificity required in four states rises to the level of mandatory phraseology.<sup>5</sup> For example, Ohio's Revised Code Section 2133.02 requires that "the declarant's declaration shall use either or both of the terms 'terminal condition' and 'permanently unconscious state' and shall define or otherwise explain those terms in a manner that is substantially consistent with the provisions of [the specified code section]." Moreover, the declarant's wishes must be communicated by "including a statement in capital letters or other conspicuous type, including, but not limited to, a different font, bigger type, or boldface type, that the declarant's attending physician may withhold or withdraw nutrition and hydration [under conditions specified in the act]."
4. *Witnessing requirements and restrictions.* In most states, two adult witnesses are sufficient for executing a directive, although witness qualifications—or, rather, disqualifications—can be many. Many states disqualify the named agent, the treating health care provider, or staff from acting as a witness, and some go much further. For example, South Carolina's Code Section 62-5-504 also disqualifies the individual's spouse and relatives; anyone directly financially responsible for the individual's medical care or entitled to any portion of the individual's estate; a beneficiary of a life insurance policy of the individual; and anyone who has a claim against the individual's estate. Three states require the directive to be both witnessed and notarized,<sup>6</sup> and six states impose special witnessing requirements on directives executed in an institutional setting.<sup>7</sup>
5. *Limitations on who may serve as agent or proxy.* Most states restrict who may serve as agent or proxy, most typically the treating health care provider or employees of the treating facility, although exceptions for relatives are common. In three states, agents must accept their appointment in writing.<sup>8</sup>

The legal transactional approach also uses an array of mandatory procedures or substantive limitations (Hickman et al. 2008). For example,

1. *Diagnostic prerequisites.* All “living will” statutes impose medical diagnosis prerequisites before taking action (usually a diagnosis of terminal condition or permanent unconsciousness), but a dozen states also require a diagnostic precondition before an agent may forgo life-sustaining procedures. The complexity of the process of diagnosis and documentation also varies.
2. *Pregnancy limitations.* A majority of states impose limitations on implementing advance directives if the patient is pregnant.
3. *Extraordinary procedure bans.* Twelve states include limitations that prohibit a surrogate from consenting to medical interventions that are especially consequential or controversial, such as sterilization or abortion or psychosurgery.
4. *Nutrition and hydration limitations.* Thirty-three states have special limitations on consent by agents, default surrogates, or guardians to forgo artificial nutrition or hydration. These range from an absolute bar on default surrogates to required diagnostic preconditions.

### *Critique of the Legal Transactional Approach*

The legal transactional approach to advance directives began with the goal of empowering patients to control medical decisions in advance through a document setting forth their instructions. Unfortunately, this approach may have served to impede rather than promote effective health care planning for the end of life. An ample body of research, summarized by Fagerlin and Schneider (2004) and others (Wilkinson, Wenger, and Shurgarman 2007), reveals that conventional advance directives have had relatively little impact on end-of-life decision making. In sum, some of the significant reasons for the lack of impact include the following:

1. *Too few people use the legal tools.* While the percentage of adults completing advance directives has increased modestly over the years, a 2007 AARP poll found that the overall completion rate of either a living will or a health care proxy document was only 29 percent. Not surprisingly, this percentage varies by age, with persons aged thirty-five to forty-nine reporting a 24 percent completion rate, aged fifty to fifty-nine a 39 percent rate, and aged sixty and older a 51 percent rate (AARP 2008). Nonwhite racial and ethnic groups tend to have less knowledge about advance

directives and are less likely to support the use of advance directives (Kwak and Haley 2005). Individuals in long-term care facilities have higher, though still modest, rates of completion. The Facts on Dying data project of Brown University's Center for Gerontology and Health Care Research reports that the use of formal advance directives by all U.S. nursing home residents in 2001 averaged 36.4 percent. The state average range varied dramatically from 15 to 68 percent (Brown University 2009).

2. *When people use these legal tools, they do not understand the forms they complete or the future decisions that might have to be made.* As Fagerlin and Schneider point out, most people find it difficult to “conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments” (2004, 33). In one study of the statutory advance directive form in Maryland, 41 percent of a sample of relatively healthy, community-dwelling senior volunteers who completed the state form were internally inconsistent in the options they selected on the form. Moreover, between 4 and 45 percent were inconsistent in the options selected on the form compared with responses they gave to various scenarios presented in a follow-up interview (Hoffmann, Zimmerman, and Tompkins 1996). The complexity and literacy demands of these forms can pose a significant challenge to their use by the public.
3. *The forms themselves do not provide much guidance.* In a review of the medical charts of 4,804 patients enrolled in the SUPPORT project, Teno and colleagues identified 569 (14%) patient charts with some form of advance directive (1997). But only ninety directives contained additional instructions beyond those of a standard living will, and only thirty-six of these addressed life-sustaining treatment in the patient's present medical circumstances. The authors concluded that even if all of these directives had been noted and rigorously followed, the effects on the overall population would have been imperceptible. Even when specific guidance is included, evidence suggests that most people prefer to give their surrogate decision makers substantial leeway in making decisions (Hawkins et al. 2005).
4. *Patients' goals and preferences for care may change.* Although studies of the stability of patients' preferences show mixed results, all show some level of preference change, sometimes significant.

For example, in a two-year study of 189 community-dwelling persons aged sixty and older with advanced chronic conditions, the researchers found that when participants were asked about their willingness to risk physical disability in order to avoid death, 48 percent changed their mind over a two-year period either positively or negatively, and likewise, 49 percent changed their willingness to risk cognitive disability. Not surprisingly, those participants whose health varied over time were somewhat more likely to have inconsistent trajectories (Fried et al. 2007).

5. *When individuals name an agent or proxy, the agent seldom understands the principal's wishes.* A meta-analysis of sixteen studies examining the accuracy of both patient-designated and next-of-kin surrogates in stating patients' wishes in specific scenarios found an overall rate of accuracy of 68 percent, with no difference in accuracy between patient-appointed and next-of-kin surrogates (Shalowitz, Garrett-Mayer, and Wendler 2006). However, family surrogates' judgments were generally more accurate than physicians' (Coppola et al. 2001). Almost all studies of surrogates' accuracy in predicting patients' wishes are based on responses to hypothetical situations and thus rely on a premise that their responses would be the same in an actual situation. These stability studies, however, cast doubt on that premise. A Spanish proverb perhaps best captures the problem: "It's not the same thing to talk of bulls as to be in the bullring."
6. *Even if individuals have completed a directive, health care providers usually do not know about the directive.* Many of the reasons for this are intuitively obvious. Individuals may rely on their family members or health care agent to produce the directive if and when needed. Even when individuals want to put their directives into the hands of a treating physician, they often have no idea who that physician will be or in which medical setting their care will be provided. Those details can change often. One study found that the medical charts of patients who had completed living wills before being hospitalized contained accurate information about their directives only 26 percent of the time and that only 16 percent of the charts contained the actual form (Morrison et al. 1995). Even when the directive is in the chart, medical records themselves can be cluttered and voluminous, and consequently, a directive may not be detected.

7. *Even if providers know that an advance directive exists, it does not significantly affect patients' care.* One study of decision making by internists found that they frequently made treatment decisions that were not consistent with an explicit advance directive, not because of problems with the directive, but because in difficult clinical situations, the internists apparently considered other factors such as prognosis, perceived quality of life, and the wishes of family or friends to be more determinative than the directive (Hardin and Yusufaly 2004). Other recent empirical evidence, however, does suggest that completing an advance directive is modestly associated with dying in place (i.e., home or nursing home) rather than in a hospital (Degenholtz, Rhee, and Arnold 2004); a greater use of hospice; fewer reported concerns with communication; and a lower probability of using a feeding tube or respirator in the last month of life (Teno et al. 2007). Whether these associations have a causal relationship is not known.

The 1997 report by the Institute of Medicine (IOM) on improving care at the end of life questioned the value of conventional advance directives:

The committee, while recognizing the value of advance directives, questions the urgency of intensive efforts to universalize their use. In this area of decision making at the end of life, the law's favorite product—the legally binding document—may sometimes stand in the way of, rather than ease, the process, especially if these documents are naively viewed as ultimate solutions to the difficulties of decision making. Rather, the documents known as advance directives should be seen as a set of tools useful in the ongoing process of advance care planning. (IOM 1997, 203)

### *The Communications Approach*

In response to the shortcomings of the legal transactional approach, an alternative paradigm has emerged, which could be called a “communications approach.” This paradigm derives from the concept of advance care planning:

Advance care planning is a broader, less legally focused concept than that of advance directives. It encompasses not only preparation of legal

documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions . . . , and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families. (IOM 1997, 198–99)

Advance care planning is an iterative process over time to discern the individual's priorities, values, and goals of care and to engage a proxy and others who may participate in the health care decision making process in the future (Collins, Parks, and Winter 2006; President's Council 2005; Tulsy 2005). The call for an expanded approach to advance care planning is by no means new, but only fairly recently have its implications for public policy, as reflected in advance directive laws, been directly addressed. The well-known tract by Fagerlin and Schneider (2004) called for the elimination of living wills and greater emphasis on the use of durable powers of attorney for health care. Lo and Steinbrook (2004, 1502) also recommended a radical simplification of these statutes:

Legal requirements that were intended to protect patients may be counterproductive. Requirements that written advance directives be witnessed or notarized place burdens on patients who complete them. . . . Advance directives would be more useful if they emphasized advance care planning, particularly discussions of end-of-life care with physicians, rather than completing a legal document. . . . Documentation of discussions is important, but should not be so complicated as to discourage the discussions themselves. . . . Patients should be able to designate health care proxies through oral statements to physicians.

While state advance directive law is far from the model advocated by Lo and Steinbrook, the growing prominence of a communications approach is reflected in incremental but real steps toward simplifying state law, especially with respect to mandatory forms or language. As noted earlier, the model for simplification is the 1993 Uniform Health-Care Decisions Act, which has prompted a number of states to combine disparate pieces of health care decisions provisions into comprehensive acts. Another possible measure of simplification is inquiring whether state law has become uncomplicated enough to enable a single advance directive form to meet the statutory requirements of all fifty states

and the District of Columbia. The Five Wishes advance directive may provide one such measure.

In the last ten years, the Five Wishes advance directive, created by the organization Aging with Dignity (2010), has been the only form actively marketed nationally. In drafting the Five Wishes, Aging with Dignity sought to create a single, personal, easy-to-use, and nonlegalistic instrument that would meet the diverse statutory requirements in as many states as possible. I compared Five Wishes with the statutory requirements in all fifty states and the District of Columbia at the time it was released for national distribution in 1998 and periodically since then to ascertain its statutory compliance (Sabatino 2005).

In 1998, Five Wishes ostensibly met the statutory requirements in thirty-three states and the District of Columbia (Aging with Dignity 1998). By 2010, the number of state laws friendly to Five Wishes had grown to forty-two and continues to rise (Aging with Dignity 2010). The increase was made possible by the trend toward the simplification of state law regulating advance directives.

Another instructive measure of simplification is a trend toward the statutory recognition of oral advance directives documented in the patient's record. Before the 1993 Uniform Health-Care Decisions Act (Uniform Law Commission 1993), no state recognized oral advance directives, but now at least fifteen states recognize some form of oral directive.<sup>9</sup> Most of these states follow the approach of the Uniform Health-Care Decisions Act, which recognizes as valid an oral "instruction" documented in the record and an orally designated "surrogate" whose appointment is personally communicated to the supervising health care provider.

A few of these fifteen states recognize only oral instructional directives but not orally designated surrogates, and some require witnesses as a prerequisite to validity. Permitting oral directives affirms the form of communication most likely between physician and patient and provides greater accommodation to individuals with differing levels of literacy.

Apart from this legislative evolution, counseling tools for advance planning also are changing. Initially, self-help materials available to the public consisted primarily of statutory forms, instructions, and related fact sheets. Beginning in the late 1990s, self-help tools began to focus on the process of planning, the values and goals to be considered, and discussions of these matters with family, friends, proxy, and health care providers. These are essentially workbooks for advance care planning.



Although a written directive remains an outcome, greater emphasis is placed on the process, not the form.

Robert Pearlman and colleagues (1998), at the Veterans Administration Medical Center in Seattle, produced one of the first of these tools in 1998, entitled *Your Life Your Choices—Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*. Examples of others are

- *Caring Conversations*, published by the Center for Practical Bioethics (1999).
- *Finding Your Way: Medical Decisions When They Count Most*, by Sacramento Healthcare Decisions (2008).
- *The Critical Conditions Planning Guide*, by Georgia Health Decisions (1998).
- Values history techniques (Kolarik et al. 2002).
- Computer-based interactive tools (Green and Levi 2009).
- *Lawyer's Tool Kit for Health Care Advance Planning* by the Commission on Law and Aging (2005).

The *Lawyer's Tool Kit* is significant in its targeting of the legal profession, which regularly assists individuals to complete advance directives. The tool kit does not provide guidance on drafting but instead gives lawyers tools they can give to clients to help them understand the planning process, self-reflect, and discuss the subject with family, physician, and others. Although the use of these kinds of resources by no means marks the end of the transactional legal model, it does suggest the growing awareness of the central role of communication in the process.

Given the movement toward a communications model, the question arises whether such a model makes any real difference in end-of-life decision making compared with the legal transactional approach. There is, unfortunately, no research-based answer, in part because the model is still being created. More important, the answer requires rethinking the kinds of outcomes the model is intended to serve. The essence of advance care planning is captured by a broader concept of patient-centered care and the quality of communication among the individual, family, and health care providers. The conventional measures of effectiveness—that is, the accuracy of surrogate predictions or even the existence of a written advance directive, or whether there is any congruence between the directive and the care actually given—all are insufficient to capture the multiple dimensions of good communication and deliberation.

In rethinking these quality measures, Gillick identified key elements of advance planning, including patients' understanding of their overall medical condition and prognosis for both the short term and the long term; their understanding of treatment plan options and the impact they would have on the patient; and the development of general goals for treatment by both the patient and the physician (Gillick 1995). In a similar vein, Teno and colleagues suggested five elements of high-quality, end-of-life care for developing a retrospective survey of bereaved family members: (1) providing dying persons with their desired physical comfort; (2) helping dying persons control decisions about their medical care and daily routines; (3) relieving family members of the burden of being present at all times to advocate for their loved one; (4) educating family members so they feel confident to care for their loved ones at home; and (5) giving family members emotional support both before and after the patient's death (2001). Both the Gillick and Teno perspectives integrate decision making and care planning into the broader notion of patient-centered care, whose parameters far exceed the scope of this article. This patient-centered care construct echoes the fundamental ethical goal of health care decision making described in 1982 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, namely, "how to foster a relationship between patients and professionals characterized by mutual participation and respect and by shared decisionmaking" (President's Commission 1982, 36).

### A Next Step—The POLST Paradigm

Questions remain about whether the movement toward a less standardized and more flexible communications approach will have a greater impact on actual treatment decisions than have the standardized advance directive forms. A strategy that began in Oregon suggests that an additional, systematic step may be needed to bridge the gap between a patient's goals and preferences and the implementation of the actual plan of care embodied in the physician's orders.

The driver of clinical action in hospitals and other health care settings has traditionally been physicians' orders, along with standardized clinical protocols. A small but growing number of states have recognized that patients' wishes, no matter how communicated, must be methodically

factored into or translated into that medical decision making engine. In the early 1990s, Oregon experimented with a protocol, called Physician Orders for Life-Sustaining Treatment, or POLST, which targeted seriously chronically ill patients, and which has subsequently been adopted by other states (Tolle et al. 1998). There are several ways to describe the POLST process, but relevant to this article are three key tasks it aims to accomplish.

First, the use of POLST requires a discussion between the treating health care practitioner and the patient, or the patient's authorized surrogate, about key end-of-life care treatment options. The objective is to discern the wishes of the patient in light of his or her current condition and discuss the available care options as explained by the treating health care provider. An existing advance directive can help inform the discussion.

Second, the patient's wishes are incorporated into doctor's orders, which are recorded on a unique, brightly colored form that is kept at the front of the medical record or with the patient if homebound. The orders are reviewed periodically and as needed. The form covers several key decisions common to seriously chronically ill patients: cardiopulmonary resuscitation; the level of medical intervention desired in the event of emergency (comfort only/do not hospitalize, limited, or full treatment); the use of artificial nutrition and hydration; and, in some states, the use of antibiotics and ventilation.

Third, providers must ensure that the POLST form actually travels with the patient whenever he or she moves from one setting to another, thereby promoting the continuity of care decision making (Hickman et al. 2008). The order is recognized by all medical professionals across all settings.

POLST is not an advance directive; it is an advance care planning tool that reflects the patient's here-and-now goals for medical decisions that, considering the patient's current condition, could confront him or her in the immediate future. It builds on the advance directive but can also function in the absence of an advance directive through a surrogate if the patient lacks decisional capacity. Research on the Oregon experience with POLST has shown positive outcomes in preventing unwanted resuscitations by emergency medical personnel, encouraging conversations about treatment preferences, and making the patient's preferences for treatment limitations known and respected (Hickman et al. 2004, 2009; Schmidt et al. 2004).

Another way to understand the POLST paradigm is as an extension of out-of-hospital do-not-resuscitate orders, which were described earlier and are recognized in almost every state (Hickman et al. 2008). POLST is similar, except that it is not limited to the single decision of resuscitation, and it does not presumptively call for withholding medical interventions. Instead, it permits a full range of plans from comfort care to full treatment.

As of late 2009, eleven states had adopted versions of POLST, often called by different names, such as POST (Physician Orders for Scope of Treatment) in West Virginia, or COLST (Clinician Orders for Life Sustaining Treatment) in Vermont,<sup>10</sup> and other states are considering similar legislation or regulation. The POLST paradigm represents a sea change in advance care planning policy by standardizing providers' communications to prescribe a plan of care in a highly visible, portable way, rather than focusing solely on standardizing patients' communications.

The POLST paradigm has the additional advantage of being fairly adaptable in the face of variable state law. For example, it has been implemented both with legislation (as in West Virginia) and without legislation through collaboration among health professionals (as in Oregon). POLST protocols can be implemented statewide and/or locally depending on legal and clinical receptivity. And even though POLST is a paper-driven protocol, it is adaptable to electronic medical record environments. Its primary distinction with respect to advance care planning is that by necessity, it focuses on immediate potential decisions and not on distant goal-based planning. Thus, the relevant population for POLST is persons with advanced chronic progressive illness, those who might die in the next year, or anyone else wishing to further define their preferences of care. In the time frame of advance care planning, POLST comes into the picture in the later stages.

To be sure, POLST is not a panacea for shortcomings of advance directives or advance care planning. Indeed, if implemented without meaningful engagement between treating health care professionals and patients or surrogates, POLST risks morphing into a formulaic clinical practice that reinforces clinicians' domination over care decisions, heedless of patients' perspectives. It can also easily be misperceived as replacing all other notions of advance care planning, even though it is intended only to facilitate the later stages of advance care planning

when a care plan to address the present needs of seriously chronically ill patients is most critical.

## Implications for Policymakers

Most Americans today will live to old age, and as a group, they will be healthier and more educated than earlier generations. Yet, they also will cope with one or more chronic conditions for an extended period of time, spend some years living with disabilities at the end of life, and face decisions that will affect the timing and quality of death (Lynn 2004). Planning is no longer just a good idea; it is an imperative. But to facilitate that imperative effectively, public policy and health care systems will need to find more effective ways to make planning routine for all adults, accommodate the myriad communication styles of individuals, and ensure that patients' goals and wishes are reflected in actual treatment plans.

While the states still exhibit a great deal of variability in advance planning law and policy, they have made significant strides toward these goals by getting the law out of the way of good planning—that is, making it simpler, less legalistic, and more adaptable to personal modes of communicating and decision making—while at the same time balancing those goals with vigilance for the protection of vulnerable persons for whom life and death decisions are being made. Progress in this direction can be measured by the degree to which states embrace a legislative model more in line with the Uniform Health-Care Decisions Act, thereby making usable a variety of planning tools in and across any state, as well as documented oral directives, and flexible reliance on family surrogates in the absence of an appointed proxy.

Perhaps the most important recent change in state policy has been the states' growing willingness to tackle the task of ensuring that patients' goals and wishes, however expressed, are actually incorporated into a care plan with teeth. Physician Orders for Life-Sustaining Treatment and its iterations represent a promising experiment in respecting patients' wishes and continuity of care.

Federal policy can undoubtedly have an enormous impact on the health care decision making landscape, for better or for worse, although historically, the federal government has played a relatively modest role. Because proposals for more assertive federal action have occurred in every

Congress since 1990, some of the more salient proposals are considered here. The most direct intervention, the creation of a federal advance directive for the general public, is not likely, given the states' traditional authority in this field. Moreover, such a creation could have a negative impact, potentially reinforcing a one-size-fits-all standardized form and reversing the progress made toward a meaningful communications approach to advance planning.

The House health reform bill, under consideration in late 2009, included a provision to reimburse physicians under Medicare for periodic voluntary advance care planning consultations with patients (U.S. House of Representatives 2009). The consultations also would include discussion of "physicians' orders for life-sustaining treatment" in states where such orders are available. The emphasis on discussion and planning rather than on forms would put the proposal squarely in line with the positive evolution described in this review. Yet, the opposition to any proposals to pay for consultations that included the topic of death was strikingly demonstrated by untethered allegations that the government intended to require counseling of seniors every five years to tell them how to end their lives sooner (Blumenauer 2009).

In practical terms, third-party payment for consultations would likely make them more frequent for Medicare beneficiaries, but not necessarily more competent, meaningful, or effective. Quality measures and quality improvement efforts become critical but are difficult to achieve.

More could have been done in the health reform proposals of 2009 to ensure that POLST became available in all states simply by requiring that providers under Medicare and Medicaid have a process in place to convert treatment goals and preferences into medical orders applicable across all care settings. That is what the POLST paradigm accomplishes. But even without a federal push, states appear increasingly willing to embrace a POLST type process.

Another federal strategy, generally overlooked but potentially profound in impact, is the simple affirmation of basic constitutional and common law principles. An unintended consequence of the proliferation of advance directive forms embodied in state statutes is that the statutory form comes to be seen by all parties as the only safe approach, thus reinforcing the one-size-fits-all shortcoming of advance directives. That perception can exist, even though the state law may specify the optional status of the form and even though both common law and constitutional law principles clearly require health care providers to respect their

patients' known wishes. A simple strategy to promote the communications model of advance planning would be to affirm this principle in federal Medicare and Medicaid law. Idaho provides an example of this strategy. The statement of purpose in Idaho's Code Section 39-4508(3) states: "Any authentic expression of a person's wishes with respect to health care should be honored."

This statement does not create any new rights or obligations in Idaho; it merely recites in simple terms a fundamental common law and constitutional principle. Applied to any clinical setting, it focuses the inquiry on accurately determining the person's wishes and goals rather than on whether the individual accurately complied with legal formalities. This principle often gets buried under the legalistic formalities of state laws. So, by expressly communicating and applying the principle to those providers who participate in Medicare and Medicaid, Congress could clarify the proper role of statutory advance directives as a means of communication, but not the only one. Affirmation of the principle could also encourage the development and use of a variety of nationally distributed advance directive tools without creating a federal model form.

Other recent proposals for federal policy have focused on matters such as addressing the portability of advance directives, supporting advance directive registries, and initiating community education campaigns, professional education, or clearinghouses (U.S. Senate 2009). These are worthy objectives but peripheral to the underlying systems of advance care planning in place. The priority objective will continue to be enhancing the evolution toward a more realistic, communications model.

Such a model should be adaptable across the wide array of cultures and special populations represented in society. The values of equal protection and equal opportunity suggest a federal role in supporting research and demonstration efforts to ensure culturally inclusive public policy with respect to health care decision making. Such research seldom occurs on a large scale without a federal commitment of resources to the field.

In conclusion, if Congress chooses to consider taking action in this area, it should consider options in the context of the central trends in state advance planning policy, that is, the movement of the states away from a legal transactional mode of advance planning toward a communications model. While much of the evaluative scholarly literature supports this trend, many questions remain about how to create authentic and reliable communication that actually and positively affects the care received. In

the meantime, states and the health care institutions within the states will continue to serve as the primary laboratory for advance care planning policy and practice.

## Endnotes

1. 1983 Cal. Stat. ch. 1204, §10, at 4615–22 (enacting Cal. Civ. Code §§ 2430–2443).
2. For example, Florida law defines “close personal friend” as “any person 18 years of age or older who has exhibited special care and concern for the patient, and who presents an affidavit to the health care facility or to the attending or treating physician stating that he or she is a friend of the patient; is willing and able to become involved in the patient’s health care; and has maintained such regular contact with the patient so as to be familiar with the patient’s activities, health, and religious or moral beliefs”: Fla. Stat Ann. §765.101(c) (West 2001).
3. Of the thirteen states, six require any advance directive to be “substantially” in the form contained in the statute: Alabama Stat. § 22-8A-4(h) (2007); Kan. Stat. Ann. §58-632 (2006); Ky. Rev. Stat. §311.625(1) (West 2007); Or. Rev. Stat. Ann. §127.531 (West 2007); S.C. Code Ann. §62-5-504(C)(1)(a) and (D) (2006); and Utah Code Ann. §75-2-1104(4) (West 2007). Four states apply the requirement only to health care powers of attorney: Nev. Rev. Stat. Ann. §449.830 (West 2007); N.H. Rev. Stat. Ann. §137-J:3 (2007); Ohio Rev. Code §1337.17 (West 2007); and Tex. [Health and Safety] Code Ann. §166.163 (Vernon 2007). Three states apply the requirement only to living wills: D.C. Code §7-622(c) (2007); Ind. Code §16-36-4-9 (West 2007); and Minn. Stat. Ann. §145B.04 (West 2007).
4. Nev. Rev. Stat. Ann. §449.830 (West 2007); N.H. Rev. Stat. Ann. §137-J:3 (2007); Ohio Rev. Code §1337.17 (West 2007); Or. Rev. Stat. Ann. §127.531 (West 2007); S.C. Code Ann. §62-5-504(D) (2006); Tex. [Health and Safety] Code Ann. §166.163 (Vernon 2007); Vt. Stat. Ann. tit. 18, §5276 (West 2007); Wis. Stat. Ann. §155.30(1) (West 2007).
5. Ind. Code §30-5-5-17 and § 16-36-1-14 (West 2007); Mich. Comp. Laws Ann. §700.5507(4) (West 2007); N.C. Gen. Stat. Ann. §90-321 (West 2007); Ohio Rev. Code § 2133.02 (A)(2) & (3) and § 1337.13(E) (West 2007).
6. Mo. Ann. Stat. §404.705(3) and §404.810 (West 2007); N.C. Gen. Stat. Ann. §32A-16(3) (West 2007); W. Va. Code Ann. §16-30-4(a) (West 2007).
7. Cal. Prob. Code §4675(a) (West 2007); Conn. Gen. Stat. §19a-576(b) and (c) (West 2007); 16 Del. Code §2511(b) (West 2007); N.Y. Pub. Health Law §2981(2)(b) and (c) (McKinney 2007); N.D. Cent. Code §23-06.4-03, §23.06.5-10(2) and (3) (2007); Vt. Stat. Ann. tit. 18, §5271(b) and (c) (West 2007).
8. Mich. Comp. Laws Ann. §700.5507 (West 2007); N.D. Cent. Code §23-06.5-06 (2007); Or. Rev. Stat. Ann. §127.525 (West 2007).
9. The statutory provisions validating oral advance directives are Alaska Sta. §13.52.010(a) and 13.52.030(c) (West 2007); Cal. Prob. Code §§4623 and 4711 (West 2007); Conn. Gen. Stat. §19a-578 (West 2007); 16 Del. Code §2507(b) (West 2007); Fla. Stat. Ann. §§765.101(1) and 765.101(11)(a) (West 2007); Haw. Rev. Stat. §327E-3 and §327E-5 (2007); La. Rev. Stat. Ann. 40:1299.58.3(3) (West 2007); 18-A Me. Rev. Stat. Ann. §5-802(a) (West 2007); Md. Health-Gen. Code Ann. §5-602(d)(1) (West 2007); Miss. Code Ann. §§41-41-205(1) and 41-41-211 (West 2007); N.M. Stat. Ann. §§24-7A-2(A) and 24-7A-5 (West 2007); Tenn. Code Ann. §68-11-1803 and -1806 (West 2007); Utah Code Ann. §75-2a-103 and -107 (2008); Va.



Code Ann. §54.1-2982 and 54.1-2983 (West 2007); Wyo. Stat. Ann. §35-22-403(a) (2007).

10. States adopting versions of Physician Orders for Life-Sustaining Treatment are California, Hawaii, Idaho, New York, North Carolina, Oregon, Tennessee, Utah, Vermont, Washington, and West Virginia. Information on POLST developments in all the states is available at <http://www.polst.org> (accessed April 1, 2010).

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