Patients, Providers, and the PSDA

by Fenella Rouse

There is little doubt that the Patient Self-Determination Act (passed as part of the Omnibus Reconciliation Act of 1990 and effective 1 December 1991) was given impetus by the Supreme Court decision in Cruzan and the publicity that surrounded the case. The Cruzan family were eloquent spokespeople for the plight of incompetent and helpless people who could be given medical treatment they might not want. The Cruzans also brought home the reality of contemporary medicine’s capabilities.

Although work began on the bill long before the Supreme Court issued its decision, press reports that (erroneously) described the case as requiring clear and convincing evidence before treatment could be stopped, fueled the public interest in advance directives and increased public understanding of what an advance directive is.

Introduced by Senators John C. Danforth (R-Mo.) and Daniel Patrick Moynihan (D-N.Y.) in October 1989, the PSDA was intended to empower people to take part in the decisions that affect the duration and condition of their lives. Its sponsors intended to correct the balance of the relationship between health care consumers and providers, which in Danforth’s perception had tilted toward “neglecting the caring component of medicine and trampling on the rights of patients” (Elizabeth McCloskey, “The Patient Self-Determination Act” Kennedy Institute of Ethics Journal 1, no. 2 [1991]: 163-69). Danforth believed the public would greatly benefit by being given information about state laws governing health care decisionmaking.

The act’s sponsors originally hoped to mandate passage of natural death or health care proxy legislation in every state. Constitutionally suspect, this was also strenuously opposed by groups such as the U.S. Catholic Conference who disfavored federal intervention and federal standards. Some groups representing institutional providers also challenged a federal role in requiring that information be provided to patients. Hospitals thought it would be inappropriate for them to give legal rather than medical advice to their patients—a concern that was addressed in the final act by requiring the states themselves to develop the information institutions would hand out. To those who preferred that information be given to patients by physicians rather than institutions, the Health Care Financing Administration argued that the administrative burden of monitoring individual physicians for compliance would be enormous and practically impossible.

The act as passed does not answer every question and did not intend to. Its underlying assumption is that if informed of their rights many more people will take advantage of them, and that if actively involved in the decisions made about medical care, more people will get care that is responsive to their needs. Such care will by definition be better, and given the perception of uncontrolled, unwanted, costly care, it was thought, may even be cheaper too. As a social experiment in involving people in advance planning for medical care, implementing the act will provide valuable information.

As enacted, the law applies to all health care institutions (hospitals, nursing facilities, hospices, home care programs, and HMOs) receiving Medicare or Medicaid. It requires that all individuals receiving medical care be given written information about their rights under state law to make decisions about that care, including the right to accept or refuse medical or surgical treatment. They must also be given information about their rights to formulate advance directives such as living wills and durable powers of attorney for health care. Institutions must prepare policies consistent with state law that allow individuals to exercise these rights and will be responsible for documenting in each individual’s medical record whether he or she has executed an advance directive.

The states must develop a written description of their own laws (whether statutory or case law) to

Fenella Rouse is executive director, Concern for Dying/Society for the Right to Die, New York, N.Y.
be given to patients. The actual substance of the law concerning our rights to make our own decisions about medical care remains largely a matter for the states to determine. Information about state law approaches to continuing or withdrawing treatment from decisionally incapable patients who have not executed advance directives should be included in the state descriptions of law. The PSDA does not, of course, provide new answers, but where states have already acknowledged families’ roles, the PSDA will assist in making that information more widely known.

The written information required by the law must be given out by hospitals at the time of the individual’s admission as an inpatient; by nursing facilities when the individual is admitted as a resident; by home health agencies and HMOs when the individual enrolls; and by hospices when care is first given. In addition, institutions are required, either on their own or with others, to undertake public education programs for staff and the community on issues concerning our rights to choose our own care.

The law does not require individuals to complete advance directives. It specifically states that facilities may not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive. Nor does the federal law override any state law that would allow a health care provider to object on the basis of conscience to implementing an advance directive.

The federal role in implementing the new law is mostly informational: the Secretary of Health and Human Services is required to develop a national education campaign to inform the public of the option to execute advance directives and of a patient’s right to participate in and direct health care decisions. The secretary is also required to develop or approve national information that would be distributed by providers to inform the public and medical and legal professions of each person’s rights in this area. Thirdly, the secretary is required to assist the states in developing the state-specific written information required by the act and in disseminating that material to the providers for them to distribute to patients. Finally, the secretary is required to mail information to Social Security recipients and add a page to the Medicare handbook describing the new law.

### PSDA in the Nursing Home

by Sandra Johnson

A s long-term care providers comply with the Patient Self-Determination Act they will confront the substantial differences that exist between nursing homes and hospitals in relation to health care decisionmaking. These differences arise first from the notion that nursing home care is less trustworthy than hospital care and requires more public oversight. Second, the regulatory system applicable to nursing homes is quite different from that applicable to hospitals and other caregivers and has a significant impact on treatment decisionmaking. A third difference between nursing homes and hospitals lies in the structures of caregiving and governance in most nursing homes. Finally, the informed consent model of health care decisionmaking has not found a precise fit in nursing home care.

In *Conroy* (486 A.2d 1209 [N.J. 1985]), the New Jersey Supreme Court established a special regime for discontinuation of treatment in nursing homes which required, among other things, that a state Nursing Home Ombudsman be notified prior to any discontinuation of treatment. The ombudsman was directed by the court to consider every notification of withdrawal of life-sustaining treatment as a possible abuse and, in consequence, to conduct an investigation. The contrasts between this approach and that of the same court in *Quinlan* are quite obvious and relate to the court’s view that nursing homes require more public scrutiny than do hospitals. More recently, in *Greenspan* (558 N.E.2d 1194 [Ill. 1990]) it was argued that withdrawal of a feeding tube from an incompetent patient would always violate Illinois law re-
Requiring nursing homes to provide shelter and assistance with meals and prohibited neglect of nursing home residents. Although the court ultimately rejected this claim, these two cases provide some glimpse of a deeply held assumption concerning nursing home care: that withdrawal of treatment is abusive and illegal. Whether nursing home residents as a group should be treated differently from other individuals in regard to treatment decisions is a public policy question that remains unresolved.

Regulations governing quality of care in nursing homes are quite different from those applicable to hospitals, and that too has had an impact on how refusal of treatment are handled. Unlike the regulation of hospitals, nursing home regulation does not initially defer to the judgment of the individual health care providers or to the internal quality assurance mechanisms of the facility. Rather, enforcement is a high priority, capturing the lion’s share of the budget for enforcing health care regulations in most states.

The emphasis on enforcement and supervision by public agencies makes administrators risk averse to any action that would attract investigation. Substantively, the regulatory emphasis on treatment, which tends to view nontreatment as an abuse or violation of standards unless proven otherwise, makes discontinuation of treatments risky. Despite changes that allow withdrawal and withholding of treatment, in practice institutional policies on advance directives may still reflect a fear of nontreatment.

Thus in complying with the Patient Self-Determination Act, facilities may communicate a de facto requirement of a written advance directive prior to decisions to discontinue or forgo treatment. In addition, the written material given to residents concerning their rights under state law might overemphasize the regulatory policies of the state agency over the rights created for patients under other state statutes or case law.

Nursing homes typically, though not always, will be less prepared to develop institutional policies as mandated under the PSDA. Most nursing homes do not have institutional ethics committees in place and so lack the experience and the structure for policy making and education in ethics that is ordinarily available in hospitals.

Finally, both the Cruzan case and the Patient Self-Determination Act elevate advance directives among the several bases and methods for health care decisionmaking for incompetent patients. Advance directives rely on an informed consent model of decisionmaking and usually require that a patient be categorized as either competent or incompetent. This bright line assumed to exist between capacity and incapacity is not reflected in the experience of nursing home providers. More frequently, the capacity or incapacity of an individual wavers over some period of time.

In the context of long-term nursing home care, the content and form of the advance directive is important. Most “living wills” will be inadequate to the task because they tend to be limited to situations in which the individual is near death or is permanently unconscious and do not extend to the majority of incompetent nursing home residents. The directive must take into account decisions that do not arise or at least arise differently in a hospital, including the decision to transfer to a hospital. Documents designating a proxy will require updating as friends and family die or otherwise become unavailable. Although the act appears to treat health care institutions as self-contained, this is not the reality for long-term care. There must be coordination of policies among the several providers likely to deliver care to a long-term care patient—including the hospital that might receive the patient for surgery; the home health agency to which the patient might be discharged or from which the patient might be admitted to the nursing home; and the hospice program in which the nursing home patient might be enrolled.

Long-term care providers can respond to the requirements of the Patient Self-Determination Act. Whether compliance with the act will have the salutary effect of shifting the emphasis from regulatory requirements toward patient-directed decisionmaking or simply solidify assumptions already in place remains to be seen.
Trumping Advance Directives

by

Dan W. Brock

When, if ever, should a patient’s advance directive not be followed? Since it is widely accepted that a competent patient’s treatment choice must be respected, and an advance directive can reasonably be understood as the treatment choice of a patient while still competent, some believe that informed, voluntary advance directives should always be followed. However, there are several reasons for special doubts about whether an advance directive accurately reflects what the patient would have wanted.

Uncertainty as to how closely an advance directive reflects what a patient actually would want may arise from any of several sources. Advance directives typically require individuals to predict what they would want well in advance of the use of the directive in treatment decisionmaking, and so treatment choices in advance directives often inevitably are less well informed than competent patients’ contemporaneous choices. For example, new, highly beneficial treatment may have been developed of which the patient was unaware; or if the directive is very old there may be evidence that the patient’s wishes about treatment have changed. Also, advance directives must often be formulated without knowing what it will be like to experience the radically different conditions in which later treatment choices must be made. Further, advance directives are often formulated in somewhat vague or general terms, which inevitably leaves significant discretion in applying them to later treatment choices and, in turn, uncertainty about whether they have been correctly interpreted.

Moreover, when competent patients make choices that appear to be seriously in conflict with their well-being or settled preferences and values, these choices will typically be questioned, explored, and even opposed by their physicians, family members, and others who care for them to insure that the patients fully understand the nature and implications of their choices, and that the choices are what they “really” want. Directives executed by no longer competent patients obviously cannot be similarly clarified. Finally, advance directives are often framed with implicit assumptions about the conditions in which the directive will be applied. For example, an advance directive declining CPR may be intended by the patient to apply to circumstances where her overall condition has so deteriorated that she is virtually certain not to survive the attempt. The patient may not have meant her directive to apply, however, should a cardiac arrest be caused by a medical procedure or in reaction to a drug, and in circumstances where CPR is highly likely to succeed and to leave the patient unimpaired.

In the second kind of case in which an advance directive might be trumped, what the individual executing the directive really wanted need not be in doubt. Instead, the issue is the moral authority of that individual’s advance directive to determine the patient’s treatment. That authority can be called into question when the directive appears to be seriously in conflict with important interests of the present patient or the patient has suffered such profound cognitive changes—for example, being now in a persistent vegetative state or severely demented—that there are doubts whether personal identity is maintained between the person who executed the advance directive and the present patient. The strongest cases of this sort for trumping advance directives will be when both these conditions obtain, with directives requesting either the forgoing of treatment or maximally aggressive treatment. For example, a person with some cognitive impairment from a stroke may have issued an advance directive that all life-sustaining treatments be forgone if he becomes significantly cognitively impaired. Though mentally handicapped, he is now otherwise healthy and with support leads a pleasant life. If he develops pneumonia that would be easily treatable with antibiotics, forgoing treatment appears contrary to his current interests.

To ensure compliance with requirements of State law . . . respecting advance directives at facilities of the provider or organization; and to provide (individually or with others) for education for staff and community on issues concerning advance directives.

Dan W. Brock is professor of philosophy, Brown University, Providence, R.I. This draws on work done with Allen Buchanan.
The third general kind of case in which an advance directive might be trumped is when the interests of others warrant not honoring it, just as they can limit the decisionmaking authority of a competent patient. In the more common scenario of a directive refusing certain forms of care, only in a very few cases should the interests of others override the patient’s advance directive. For example, in treating patients very near death physicians sometimes say that they are principally treating the family, not the patient. What is often meant is that the treatment being provided will have little effect one way or the other on the interests of the patient, who will die very soon whatever is done, but may have a great effect on the surviving family and how they are able to deal with the patient's dying and death. Stopping treatment might then be very briefly delayed to help the family accept the patient’s death. In the case of an advance directive asking for particular treatments, limits on the authority of advance directives can apply: when the treatment requested will be funded by the resources of others and exceeds the just level of health care that should be provided from those sources, public procedures might justly deny that care. So too it may be ethical not to honor the patient’s directive asking for treatment if doing so would seriously violate the moral or professional integrity of the treating physician; for example, if the patient’s directive requests treatment that would now be certain and completely futile. However, in many such conflicts transfer of the patient’s care to others who can honor the advance directive is appropriate.

The issue for public policy, then, is what procedures should be required before an advance directive is set aside or overridden. Because of reasonable fears about abuse by physicians or family members of any authority not to honor advance directives, some believe they should always be binding. A better alternative, I think, is to develop institutional and judicial procedures and safeguards to reduce the risk of abuse to tolerable levels. These procedures might require going to court for some, or even nearly all cases, and consultation with ethics committees or other institutional bodies in others. Though advance directives may not be ethically binding in all cases, they should be honored in the vast majority, and should only be set aside after careful consideration and by following procedures adequate to limit abuse.

**PSDA in the Clinic**

by

Linda Emanuel

A great majority of patients in the ambulatory setting welcome the opportunity to discuss advance planning for health care in case of mental incompetence. While it is commonly assumed that advance planning is relevant for the old or sick alone, planning with young and healthy patients may be considered analogous to screening for illness; the chance of illness is low, but the effort may be worth it.

The initiative for advance planning should come from the physician and should be understood to be part of standard care. If a patient has a document already, the physician should review and discuss it, and should recommend a clearer or more specific document if need be. Physicians should see their function as educational, guiding patients to pertinent information (bearing in mind their health status) and asking appropriate questions regarding issues raised in circumstances of life-threatening illness and mental incompetence. Specific preferences should be explored, especially where they are apparently not sensible, to correct misunderstandings or understand atypical values. Irresolvable differences in values between patient and physician that may potentially compromise the physician are indications for asking the patient to agree to transfer of care should the circumstances in question arise.

**Admission.** To the extent that the Patient Self-Determination Act aims to bring patients’ advance directives to the attention of the medical caretakers, admission to a health facility is a practical point at which to do so for a great majority of patients. But whether it is enrolling in a health maintenance organization or arriving in a hospital emergency ward, this time is not likely to be opportune for any substantive discussion of patients'
values and treatment preferences. Activities should be restricted to providing informational brochures and identifying resources and to documenting whether the patient has preexisting directives.

**Role of a health care planning nurse.** Ultimately, advance planning should occur in the context of a physician-patient dialogue. However, much of the necessary information and guidance can be provided by a nurse specializing in health care planning, especially if the nurse is provided with a health profile of the patient. Health care planning nurses should be able to inform patients and their families or designated proxies about concepts of advance planning, documents available, basic legal requirements, and so forth; they should be able to guide the patient through tentative completion of a document. They should, however, always seek to involve the physician for the actual completion of the document.

**Completing the directive.** Completing directives in the context of a physician-patient discussion is important for several reasons. Patients can be educated about what decisions are pertinent; they can be provided with illness scenarios and further information; any misconceptions they may hold can be corrected. In helping patients to refine their directives physicians are provided with a unique opportunity to gain insight into the patient’s health care goals and values. For a similar understanding, the next of kin or proxy designate should be encouraged to participate in the process of advance planning.

**What document?** Written statements are unlikely to provide for all possible circumstances, and proxy decisions are known to reflect the preferences of the patient poorly. The burden of being a proxy is also often underestimated. It is therefore necessary to combine written directives with surrogate decisionmaking.

The written statement can be guided by the use of illness scenarios allowing a patient to state his or her preferences regarding specific life-sustaining interventions. Statements about their goals for medical care in each scenario can be solicited (for example: comfort care, or dignity over longevity, or prolonging life despite suffering, etc.). More general statements about values can also be sought.*

Written directives for medical care should be considered more as interpretive guides for the physician and proxy, that is, as evidence of the patient’s wishes, than as water-tight legal imperatives. This should be made explicit in the document. Medical treatment preference statements can be appended to more formal legal documents, such as state statutory documents.

**Documenting directives.** Directives should be made a part of the patient’s active medical records and their existence flagged in some fashion. They may remain sealed until the patient is found to be incompetent to make treatment decisions. Wallet cards or bracelets noting the location of the directive should be made an option. Registries of living wills should be made available. Copies of the directive should be given to the physician if there are separate office records, to the family and proxy designate, and to any other involved party.

**Follow-up and revision.** Patients’ advance preferences have been found to be quite durable. Nevertheless, revision of preferences should be anticipated and allowed for. It is prudent to review documents routinely—at times of major life events such as marriage, new parenthood, and bereavement; at times of major changes in health status; and, whenever possible, on admission to the hospital or other health care facility.

**Implementing directives.** The next of kin or proxy designate should be given a strong role in discussing patient care decisions with the physician. The proxy’s intent should be to attempt substituted judgment for the patient. Although best-interests standards are also used by some proxies, identifying the patient’s best interests should often be left to the physician. A balanced discussion should include the patient’s statements of preference, the proxy’s interpretation of patient preferences, and considerations raised by the physician and other involved parties. Ultimately, guided by the physician and other caregivers, the proxy must try to make decisions as the patient would have done for him or herself.

---

* A document combining these features is available from Harvard Medical School Health Publications, P.O. Box 380, Boston, MA 02117.

S7
Honoring Broader Directives

by

Susan M. Wolf

Most states now have statutes on treatment directives, commonly called “living wills.” Often, however, these statutes only cover patients who are terminally ill at the time the treatment choice is to be effectuated. They may also prescribe a certain form to be followed in drafting a treatment directive. Further, they may contain substantive limitations, such as a seeming prohibition on the use of treatment directives to refuse artificial nutrition and hydration.

All of these restrictions have led many health care professionals, administrators, and even lawyers wrongly to maintain that a directive broader than the statute is without legal effect. They make the common mistake of believing that once the legislature has recognized one means of protecting individual rights, there are no other means. They misconstrue every other effort to express treatment preferences as if it were a ball hit out of bounds.

In fact, any expression of treatment preferences has legal effect. A directive broader than the statute is not out of bounds. Health care professionals are obligated to pay careful attention to such directives. But to see why, you have to understand something about the relationship of the statutory rights provided by state legislatures, the additional common-law rights recognized by judges, and the rights provided by the state and federal constitutions. Patients have all three.

Statutes on advance directives vary from state to state, but they generally provide a combination of carrots and sticks to induce health care professionals to honor a patient’s written treatment preferences. The most important carrot they hold out is civil and criminal immunity to professionals who act in good-faith reliance on a patient’s directive in forgoing life-sustaining treatment. With that kind of guarantee, there is no excuse for overriding the patient’s preferences.

Thus, state statutes create a protective umbrella, a zone in which patient preferences are protected by a system of incentives directed at health care professionals and institutions. However, that is by no means the entire domain of protected rights. It is a piece of the playing field, not the whole ballpark.

A number of state statutes actually acknowledge this. They state that the rights provided by the statute in no way reduce other rights the patient may have. In other words, the statute adds to the patient’s rights deriving from common law and constitutional law; it does not reduce those rights.

So what are these other nonstatutory rights? Judges have long since recognized that patients have a common-law right to be free of unwanted bodily invasion. This is the basis of the legal obligation to obtain a patient’s informed consent before performing invasive procedures. In case after case, judges have declared that patients have a common-law right to refuse unwanted life-sustaining treatment. That right is not confined to the terminally ill, and applies to the refusal of all life-sustaining treatment modalities including artificial nutrition and hydration. Nor does a patient even need to express the refusal in writing. Oral expressions of preference may be effective as well.

There are similar constitutional rights. A majority of the Supreme Court acknowledged in the 1990 Cruzan case that the federal Constitution protects the right of competent patients to refuse any life-sustaining treatment including nutrition and hydration. A number of state courts have said so as well. In addition, state courts have found relevant protections in their state constitutions.

When a patient loses competence, she does not lose these constitutional and common-law rights. Rather, treatment choices must still be governed by the patient’s own treatment preferences, if those can be ascertained. Any oral or written declarations from the patient are relevant evidence, including treatment directives broader than or different from the state statute. Indeed, in those states that still lack a statute on treatment direc-

Susan M. Wolf is associate for law, The Hastings Center.
On Behalf of the Patient

by

DaCosta Mason

The Patient Self-Determination Act provides an excellent opportunity to clarify some of the issues that affect those who must make health care decisions for incompetent or never competent patients. Two issues that require clarification in most states are:

- When does the surrogate’s authority commence?
- What guidelines must surrogates follow in making decisions for patients?

Health care providers utilize different standards for determining decisional capacity, and at a time when efforts have increased to keep health care decisionmaking out of the courtroom, there is also a growing need to formalize the process by which they do so. For many surrogates, the current process raises questions concerning when they have the authority to act on behalf of the patient.

While there is little question that guardians’ authority to act begins when the court signs an order appointing them, the same is not true for agents under health care powers of attorney or family members.

At least thirty-eight states and the District of Columbia have legislation creating a health care power of attorney. Under these various statutes, a health care power of attorney can become effective upon execution, on a specified date, or when the patient becomes incapacitated or disabled. Generally, physicians determine a patient’s decisional capacity. Thus, surrogate decisionmakers are controlled by the physician’s determination of their right to participate in treatment decisions even though they may be agents under a health care power of attorney that becomes effective upon execution or on a date certain. This can be-

---

DaCosta Mason is senior legal program coordinator, American Association of Retired Persons, Legal Counsel for the Elderly Department, Washington, D.C.

---

division, a patient’s written or oral preferences should govern treatment choices nonetheless.

In addition, a patient who has appointed a proxy to make treatment decisions for her in the event she loses competence enjoys legal protections. These are often enumerated in state statutes on proxy appointments, such as durable power of attorney statutes. However, Cruzan suggests that the decisions of an appointed proxy may enjoy constitutional protection as well.

The toughest cases, of course, are those in which the patient has appointed no surrogate and has failed to leave sufficient evidence of her treatment preferences to dictate the treatment choice. In most states that have considered the issue, a surrogate is then obligated to extrapolate from what is known of the patient’s values and preferences in order to figure out what the patient would choose if she could. Commonly, this decisional approach is labeled “substituted judgment.” Here again, any relevant written or oral statements from the patient would be highly important; they would constitute the basis for extrapolating the patient’s preferences. Written or oral statements are not, however, essential. Surrogates can also be guided by knowledge of the patient’s general beliefs and values.

Thus any memorialization of the patient’s treatment preferences has legal force. At the very least, it constitutes relevant evidence of the patient’s wishes. It cannot be dismissed or ignored.

This means that state statutes on treatment directives cover only a subset of those clinical cases in which health care professionals are legally bound to respect patients’ previously expressed treatment preferences. Patient preferences govern treatment decisions whether or not the patient is “terminal.” Those preferences also govern no matter what treatment the patient rejects.

Health care professionals, administrators, and lawyers must recognize that state statutes on treatment directives govern only a part of the playing field. They should not be confused by literature assuring them that they are on solid ground in honoring directives that fall within the bounds of the statute, but shaky ground outside that zone. Failure to honor a patient’s directive that falls outside the special protective regime of state statutes will almost certainly violate the patient’s other rights.
come confusing for agents in situations where they feel the patient is unable to make a health care decision and the treatment being provided is contrary to what they believe to be the patient’s wishes. Even in those situations in which the health care power of attorney becomes effective when the patient becomes incapacitated, if the document contains no definition of incapacity, the physician will once again control when the agent may participate in decisionmaking.

Some jurisdictions, such as the District of Columbia and Virginia, specifically require written certification of incapacity before a surrogate has authority to act on behalf of the patient. Two physicians, one of whom is a psychiatrist, should evaluate the patient at or near the time a decision has to be made and document the determination of incapacity in the patient’s medical record. An additional evaluation must be conducted every thirty to sixty days thereafter. This method of determining incapacity in the non-judicial setting clarifies when a surrogate could act on behalf of the patient.

Once surrogates have authority to act, what guidelines must they follow in making decisions? With increased emphasis on educating individuals about their right to participate in health care decisions, it is likely that more people will discuss their values and desires about health care with family members or other potential surrogates. This, one hopes, will increase the knowledge surrogates have about the patients for whom they will be making decisions as well as bring some consistency to the decision-making process.

Most states provide some variant of two basic standards to guide surrogates: the substituted judgment standard and the best interest standard. The substituted judgment standard requires surrogates to make a decision based on what the patient would decide, were he or she capable of doing so. The best interest standard applies when it is impossible to determine what the patient would decide. Although these standards seem very clear, in practice the distinction may become blurred, particularly when the patient’s views have not been expressed clearly.

To promote patients’ autonomy and self-determination, more emphasis must be placed on a systematic approach to guiding surrogates. First, surrogates must determine if the patient has provided explicit directions. If the patient has left written directions of any kind, they should be followed. If the patient ever made any explicit oral statements about the situation at hand, they should be followed.

Second, if the patient has left no directions about the treatment in question, the surrogates should apply the patient’s known values and preferences in an effort to make a decision as he or she would have. This requires surrogates, to the extent possible, to become more familiar with persons for whom they may have to make decisions. Therefore, only in those situations in which surrogates do not know anything about the patient would a best-interest approach be necessary.

Finally, if the surrogates know nothing about the patient, then the treatment decision should be based on what a reasonable person would choose, considering all of the available alternatives.
Community Education

by

Matthy Mezey

Perhaps the least defined and most challenging aspect of the Patient Self-Determination Act is the mandate for community education. The purposes of community education are to inform and to change behavior. In the case of the PSDA, the aim is to encourage consumers to anticipate and, if they so desire, to articulate their preferences concerning life-sustaining treatment. Within any one community, during the course of even one illness, people often use several health care facilities: a hospital, a home health care agency, a nursing home. Coordination across health care agencies is essential for effective implementation of the PSDA.

The community education component of the PSDA thus can best be accomplished by building coalitions among institutions and providers. Consortia offer several advantages over efforts of single agencies: a uniform message endorsed by many agencies has greater public credence and creates public confidence. Consortia foster participation of small institutions. Broad constituencies encourage consideration of issues that might otherwise not be incorporated into a community education program—for example, the ramification of the PSDA for various religious and ethnic groups. Consortia help create consistency across agencies, thus circumventing the confusion and conflicting information that commonly occurs when people move between health care facilities.

For consortia to be effective, each community must establish an organizational structure, whether this proves to be a statewide task force or efforts at the municipal or county level. To be fully effective, community efforts need to include not only health care professionals, but also representation from other community groups, especially churches.

Several statewide programs provide models for collaborative community education. The New Jersey Citizens' Committee on Biomedical Ethics Inc. conducted a statewide consumer survey of biomedical ethical issues and coordinates the state's PSDA community education efforts. The California Consortium on Patient Self-Determination has been formed for the specific purpose of implementing the PSDA. In Arizona, Arizona Health Decisions has joined with the Dorothy Garske Center to assist families, providers, and facilities in working together to broadly implement the PSDA.

In addition, numerous federal, professional and consumer organizations, including the Health Care Financing Administration, the American Hospital Association, the American Bar Association, the Society for the Right to Die/Concern for Dying, the National Coalition for Nursing Home Reform, and the American Association of Retired Persons are preparing materials to help providers and agencies implement the community education component of the PSDA.

The community education mandate of the PSDA lends itself to three overall goals: increasing the general public's awareness and knowledge about the act itself; providing information and consultation to constituencies and consumer groups with specialized needs for information; and surveying, monitoring, and evaluating the effectiveness of implementation of the act.

**General public awareness and knowledge.** The most pressing aspect of community education is disseminating information about the PSDA. While the act mandates only that people be informed of their right to make advance plans about treatment decisions at the time they enter a health care facility, logically this is not the ideal time to confront people with the option to make treatment decisions. Rather such decisions are best made in consultation with family and without the added stress associated with entering a health care facility. Thus, the ultimate aim of community education is to inform people about the PSDA so that, if they so desire, they enter a health care facility with already specified treatment options.
Need for information among specialized consumer groups, constituencies, and health care facilities. In addition to general public information, certain individuals, groups, and organizations have specialized needs for information about the PSDA. Families of patients with Alzheimer’s disease, for example, grapple with different issues related to advance directives as compared to families caring for developmentally disabled relatives. Nursing homes face different issues from those of hospitals or home care agencies in implementing the PSDA. And the PSDA raises difficult ethical and moral issues among different racial, religious, and cultural groups.

These differing constituencies need “customized” information and consultation to address their specific issues related to the PSDA. They also need to establish mechanisms for communicating individual or facility-level decisions so that potential conflicts with policies of other agencies and providers can be acknowledged and resolved.

Monitoring and evaluation of the PSDA. While there is general enthusiasm for the PSDA among facilities and providers, implementation does carry certain risks. Where compliance with the act is perfunctory, for example, distribution of written materials may further confuse rather than inform patients. It is unclear how institutions will interpret the treatment preferences of people who choose not to complete advance directives, or how fully institutions with limited resources or those that provide marginal care will comply. And concerns have been raised as to the potential for discrimination and coercion, especially among marginalized or extremely debilitated and institutionalized populations.

The consortium approach allows a community to periodically survey public opinion as to attitudes and concerns, and to monitor the level of implementation within institutions. Such surveys should not be viewed as punitive but rather as offering communities the opportunity to redress problems and misconceptions, and to identify innovative practices that establish a “gold standard” for community education.

California Consortium

The California Consortium on Patient Self-Determination has not only developed materials for patients, providers, and the public but has helped clarify issues for the federal officials preparing regulations to implement the act.

The Consortium—25 organizations encompassing nearly all hospitals, skilled nursing facilities, hospice and home health providers, and HMOs in the state, along with representatives from health care professional and consumer groups, bioethics centers, and the state’s Department of Health Services and Commission on Aging—joined together in the conviction that everyone affected by the PSDA would be best served if the groups cooperated and pooled their expertise and experience. In monthly meetings, as well as through the work of four task forces, the Consortium has pursued several goals.

Most important, it has written two brochures for patients. One provides basic information about the rights that California statutes and court decisions give people to make health care decisions. Those who want more details about how to prepare an advance directive will get the second brochure. Although the circumstances of different providers mandate small variations in the basic brochure, everyone will get documents that are essentially uniform whenever and wherever they are treated. Translations into major languages are also being prepared.

Besides reviewing the patient brochure, the task force on legal and regulatory matters has prepared a summary of California law as part of the PSDA Handbook that will be distributed to all health care providers.

The bulk of the Handbook has been prepared by the remaining two task forces. One has drafted model policies and procedures to aid facilities in complying with the PSDA, including points to consider in forgoing life-support, such as procedures regarding DNR orders. The other has developed training materials on health care decisionmaking and advance directives for institutions to use with their staffs, as well as educational programs appropriate for the community.

This month, providers covered by the PSDA will receive copies of the Handbook and camera-ready copy for the patient brochures, to which they can add information about their own policies and the personnel who will answer patients’ questions. Educational and train-the-trainer conferences are being organized around the state for the coming months.—Alexander Morgan Capron, codirector, Pacific Center for Health Policy and Ethics, Los Angeles, Calif.
Institutional Quandaries

by

Ruth B. Purtilo

During a recent presentation I made about the Patient Self-Determination Act to the medical staff of a nearby community hospital the following questions were among those raised by attendees:

- What information, exactly, should be made available to patients, and by whom?
- Should families be present during conversation that ensues about the act, or should the competent patient have the prerogative of whether to share the information with family members?
- When should the exchange regarding advance directives and a patient’s rights to accept or refuse treatment take place?
- Do nurses, therapists, and other members of the health care team have a role to play in implementing the act?
- Am I protected from having to follow some aspect of the act’s mandate, or the policies flowing from it, that would compromise my own moral convictions?

Institutional administrators, upon whose shoulders it has fallen to design and oversee staff education and institutional policy formation related to the act, will find the basic framework for their activities in the ethical concerns expressed through these clinicians’ questions. At least three general areas are appropriate focuses for administrators’ activities: the professional promise to maintain patient dignity and show respect for individual differences; the practical reality that high ethical standards require effective teamwork in patient care; and the societal promise that health professionals’ own professional integrity will be recognized.

Maintaining patient dignity. Administrators will differ among themselves regarding the role they believe advance directives play in realizing the act’s goal of allowing adult patients to maintain an active voice in their treatment. Whatever the administrator’s position, it would be a mistake to focus staff education and policy on advance directives alone. Advance directives have arisen in response to the challenges life-threatening illness or incapacity pose to patients’ dignity and autonomy. The act offers an opportunity for clinicians, administrators, and others to rethink the full scope of attributes and behaviors that foster a patient’s self-respect in such extreme circumstances. Particularly relevant are concerns about communication, in professional-patient and hospital-patient relationships: Alexander M. Capron creates a plausible nightmare scenario of advance directives being signed in the presence of admissions clerks only (HCR 20, no. 5 [1990]: 35-36). To be avoided at all costs is bureaucratic satisfaction that patients are being efficiently “Danforthed”—while not given the full respect they deserve. The increasing awareness that patients’ statements about end-of-life decisions must be further clarified to discern their real wishes should...
in procedures or other activities that compromise the person’s religious beliefs and other deeply held values. In our pluralistic society the PSDA challenges administrators in that it is silent on what an institution should do about employees who believe that the act presents morally reprehensible options to patients. The wording assumes that patients simply will be given all the information. At the very least, staff education should include an opportunity for the rich diversity of belief and opinion among members to be aired and dealt with in an environment of support; such education can include an emphasis on employee-generated mechanisms to exempt direct involvement of individuals whose convictions preclude them from participating in the act’s implementation in good conscience. The principle of respect for the professional as a person combined with a clear standard of what is required in the professional role the person voluntarily has assumed will be an apt guide for ascertaining the appropriate extent to which his or her convictions can be honored.

Equally important as a focus of education and policy is to spell out safeguards regarding personal religious beliefs of professionals. This, too, is an opportunity to review existing or needed institutional approaches that show respect for the professional as a person.

In summary, the act is best viewed from a staff education and policy point of view as being within the broader context of good patient care that requires competent, individualized, and thoughtful approaches to patient problems. Rather than to treat the act administratively as a unique regulation, the focus should be on policies and practices designed to maintain patients’ dignity, foster effective communication and documentation, stimulate effective teamwork, and honor health professionals’ moral beliefs.

The Spirit of the PSDA

by

Elizabeth Leibold McCloskey

The challenge that confronted Senator Danforth and others who crafted the Patient Self-Determination Act was to provide a clear directive to states and health care institutions while allowing flexibility and innovation in its implementation. Those charged with implementing the act would do well to capture its spirit by going beyond the mere letter of the law and the anticipated minimal standards to be set by the Health Care Financing Administration.

The intent of the Patient Self-Determination Act is clearly to promote widespread knowledge of advance directives, not only among Medicare and Medicaid beneficiaries but throughout the entire population. Thus the law applies to all adult patients who receive care at a health care facility receiving Medicare or Medicaid dollars. The Health Care Financing Administration, which is responsible for writing regulations for this law, will undoubtedly require that all adult patients be given information.

But the law itself is silent on the responsibilities of the health care institution with respect to incompetent patients and their guardians, as well as patients below the age of majority who may possess certain rights under state law. Should they be told about patients’ rights as the law applies to them? And what about those people who are being treated on an outpatient basis? The law explicitly cites inpatient admission procedures, but not outpatient.

These questions, some of which have been raised by the California Consortium on Patient Self-Determination, exemplify the sort of issue where it is best for those affected by the law’s requirements to adhere to the spirit rather than get hung up on complying with the letter of the law.

Elizabeth Leibold McCloskey is a legislative assistant to Sen. John C. Danforth of Missouri.

S14
The Patient Self-Determination Act was intentionally drafted in a manner that would allow HCFA's monitoring to be straightforward and nonintrusive. Thus, while the law establishes a minimal level of activity, its legislative background clearly frees, and encourages, institutions to go as far beyond the mere letter of the law as possible. In other words, it does not much matter if the law or the regulations do not require notification of outpatients, or guardians, or those under eighteen; institutions can and should do these things anyway.

Who should tell patients, when? Institutional initiative should also be an operative principle in terms of who should provide information to patients. During the course of the legislative debate, physicians (speaking through the American Medical Association) felt strongly that the law should not specify who within an institution should have primary responsibility for informing patients. Although the AMA's interest was to avoid being the subject of yet another federal requirement, the point was well made that different institutions could tap the most appropriate human resource to bear this responsibility.

The only specification found in the act is that written information be provided at the time of admission. This requirement at least ensures that patients will receive something uniformly as a part of the admissions process. Nothing precludes an institution, however, from providing the written information at admission, having an admitting or attending physician ask the patient whether she has an advance directive, and having a social worker, nurse, or chaplain talk to the patient or the family at greater length either before discharge or sometime during the hospital stay if it is appropriate.

Is a piece of paper enough? Giving the patients a piece of paper is not enough to guarantee thoughtful discussion about end-of-life care, of course. The act, and the upcoming regulations, only set the minimum standard of educational activity; anything more would have hindered flexibility and innovation. Requiring good sense and good conversation could well have stifled such things, and regulating conversation would have been overly intrusive. But that does not mean that health care institutions should stop short of fully complying with the spirit of the law, which is that advance directives be more routinely discussed and utilized. Some argued during the making of the PSDA that it was unnecessary because institutions could initiate, and were initiating, this type of educational activity on a voluntary basis. The act, however, provides the impetus for institutions to focus on their educational responsibility while not being too detailed in its requirements. Institutional initiative remains critically important to ensure that the law has an effect.

The PSDA presents a challenge to states and health care providers throughout the country: will they let the law lie there flat, demanding compliance, resulting in perfunctory implementation? Or will they seize the opportunity for the law to be the impetus to promote, responsibly and sensitively, greater knowledge of advance directives?

The impact of the PSDA hinges much less on its statutory language or on HCFA's written regulations that on personalized, nonregulated activity. The flurry of activity that has occurred at the state level, and particularly at the institutional level, suggests that the act has already had a positive impact and will continue to do so.
Selected Resources in Patient Self-Determination

Special Projects Section
American Association of Retired Persons
601 E Street NW
Washington, DC 20049
202-434-2277
A Matter of Choice (book) - single copies at no charge
Tomorrow’s Choices (brochure) - single copies at no charge

American Bar Association
Commission on Legal Problems of the Elderly
1800 M Street NW, South Lobby
Washington, DC 20036
202-331-2997
Patient Self-Determination Act State Law Guide - $5.00
(quantity discount available)

American Hospital Association
AHA Services, Inc.
P.O. Box 99376
Chicago, IL 60693
1-800-AHA-2626
Fax: 312-280-6015
Values in Conflict: Resolving Ethical Issues in Hospital Care (book, #C025002) - $20.00
Preparing for Advance Directives (videotape, #157301) - $500
Put It in Writing (book, #166908) - $25.00
Put It in Writing (brochure, #166909) - $12.00
Advance Directives: Guaranteeing Your Health Care Rights (videotape) - forthcoming - $119.00
(Member discount available for all items)

American Hospital Association Resource Center
840 North Lake Shore Drive
Chicago, IL 60611
312-280-6263
Patient Self-Determination and Advance Directives (bibliography)

Ellen Savaroni, President
California Health Decisions
505 South Main Street, Suite 400
Orange, CA 92668
714-647-4920
Durable Powers of Attorney for Health Care (kit) - suggested donation $5.00 (quantity discount available)
Durable Powers of Attorney for Health Care (brochure) - $6.25/25 copies
Partners in Health Care (videotape) - $85.00

Care Source
505 Seattle Tower
1218 Third Avenue
Seattle, WA 98101
1-800-448-5213
On Your Behalf: Your Right to Accept or Refuse Medical Treatment (video) - $69.00 ($89.00 after 11/1/91)
accompanying booklet - $0.95/copy

Center for Health Care Ethics
St. Louis University Medical Center
Orders: Virginia Publishing
P.O. Box 4857
St. Louis, MO 63108
314-367-6612
Advance Directive for Future Health Care Decisions: A Christian Perspective (booklet) - $5.00

Concern for Dying/Society for the Right to Die
250 West 57th Street
New York, NY 10107
212-246-6973
Advance Directive Protocols and the PSDA (booklet) - $10.00
Medical Treatment and Your Living Will - $3.00
About Advance Medical Directives - $1.50
A Time to Choose (videotape) - $70.00
In Sickness or in Health (videotape) - $75.00
The Right to Die...the Choice Is Yours (videotape) - $38.00

Midwest Bioethics Center
410 Archibald, Suite 200
Kansas City, MO 64111
Information: 816-756-2713
Orders: 816-756-1735
Making Health Decisions for Your Future: Advance Directives - single copies at no charge - multiple copies $0.30 each
The Letter & the Spirit, a workbook on strategies for implementing the PSDA - $10/copy, supply limited

National Reference Center for Bioethics
Kennedy Institute of Ethics
Georgetown University
Washington, DC 20057
1-800-MED-ETHX
Living Wills and Durable Powers of Attorney: Advance Directive Legislation and Issues (Scope Note 2, revised September 1991) - $3.00 prepaid

New Jersey Commission on Legal and Ethical Problems
1201 NJ 061
Trenton, NJ 08625
Advance Directives for Health Care: Planning Ahead for Important Health Care Decisions (booklet) - no charge; send SASE ($1.00 postage)

Oregon Health Decisions
921 SW Washington, Suite 723
Portland, OR 97205
503-241-0744
Making Health Care Decisions (booklet) - $3.00 (quantity discount available)

S16