The History of Advance Directives
A Literature Review

The Patient Self-Determination Act is one step needed to move to a more patient-centered health care system; nurses can aid in preserving patients' rights by helping older adults develop advance directives.

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Before 1970, health care ethics were based on professional authority and beneficence (Oddi, 1994). Physicians made all patient care decisions and focused on maximum life preservation. These decisions were grounded in religious and philosophical thought that had no provisions for personal control of the dying process. What began as medical paternalism has moved, or at least is moving, in the direction of respecting a competent patient's right to control medical interventions.

With the passage of the Patient Self-Determination Act (PSDA) in 1990, individual rights, the central value of American culture, began to be more fully realized. The PSDA mandated that patients receive information concerning end-of-life decisions, and their consequent right to draft advance directives. The PSDA and the right to draft advance directives did not create new patient rights—it just recognized the existing right of every person to control his or her own destiny.

HISTORY LEADING TO THE PASSAGE OF THE PATIENT SELF-DETERMINATION ACT

In 1914, Justice Benjamin Cardozo used the right of self-determination to justify obtaining a patient's consent for invasive medical procedures. He stated "...every human being of adult years of sound mind has the right to determine what shall be done with his own body..." (Cardozo, 1914). The development of mechanical ventilators and cardiopulmonary resuscitation (CPR) occurred in the 1930s through the 1950s. Thus, care shifted to the technical pursuit of sustaining life. Some saw this as defying nature's merciful release from death.

In the 1960s, interest in death and dying, patient's rights, and hospice care increased. Individuals thought more about humanely caring for and comforting the dying. A move to free terminally ill patients from life sustaining measures also occurred. The concept of a living will was first developed in the late 1960s by an Illinois attorney (Kelley, 1995). The consumer rights movement during this same time directly affected self-determination. Discussions were focused on the right of individuals to refuse or withdraw treatment. This was a shift from the right of informed refusal.

A pivotal case occurred in 1975. Twenty-one-year-old Karen Quinlan, a victim of substance abuse, had a cardiac arrest and was successfully resuscitated, but remained in a persistent vegetative state. In 1976, the New Jersey Supreme Court granted her parents the right to withdraw life support. The Court held that an individual's constitutional right to privacy outweighed the state's interest in preserving life (Kelley, 1995). It was stated that this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances (President's Commission, 1983). The ventilator was removed, but Quinlan breathed on her own and, sustained by tube feedings, lived until 1985. This case stimulated ethical discussions of a different nature. Now the discussion focused on whether health care professionals could ethically remove life sustaining treatments from terminally ill patients or patients in a persistent vegetative state.

In 1976, California passed the Natural Death Act. This was the first law to give legal force to living wills. Then, in 1977, Arkansas became one of the first states to pass advance directive legislation. This law authorized patients to refuse treatment that would prolong their lives. In 1983, Pennsylvania became the first state to enact legislation for durable power of attorney for health care (DPAHC) (Hackler, Moseley, & Vawter, 1989).

In 1983, another significant case occurred. Nancy Cruzan, age 32, was involved in an automobile accident that left her in a persistent vegetative state. Her parents petitioned the court for the right to withdraw life support. Seven years of court battles ensued. Finally, in June 1990, the U.S. Supreme Court upheld Missouri Supreme Court's decision that Cruzan had the right to refuse tube feedings, but that the
state could demand clear and convincing evidence that this was her expressed desire. Her parents had to provide this evidence because their beliefs about what Nancy would have wanted were inadequate. The U.S. Supreme Court, in December 1990, authorized removal of the tube feeding and Cruzan died later that month.

The 1990 Supreme Court decision cited the 14th Amendment, stating that a competent person has a constitutionally protected liberty to refuse unwanted medical treatment. This opinion strongly pointed the way to legalizing advance directives to clarify a person’s wishes. At the same time, many organizations, such as the American Medical Association, the American Bar Association, the American Hospital Association, and the Health Care Financing Administration expressed misgivings about the establishment and enforcement of a law promoting advance directives (Hassmiller, 1991). It was this climate, filled with these complex issues, which gave rise to the development of public policy allowing individuals to forego life-sustaining treatment.

**PATIENT SELF-DETERMINATION ACT**

“The movement to increase the use of advance directives arose against a backdrop of a widespread public assumption that dying patients typically receive substantial amounts of unwanted and nonbeneficial care,” according to Brock (1994, p. 59). Rising health care costs, consumerism, and advanced sophisticated technology that developed faster than the ability to manage it were the driving forces behind the development of the PSDA.

Consumers expected to experience an active feeling of well-being and sought legal alternatives, such as malpractice suits, when treatment outcomes were perceived as less than desirable. Senator John Danforth said the following:

More and more it is arguable that we play God by subjecting people to unwanted and sometimes unnecessary treatment, treatment that unnaturally prolongs the dying process. Our health care system has become obsessed with extending life, at times neglecting the caring component of medicine and trampling on the rights of patients. (Cate & Gill, 1991, p. 5)

The PSDA is a federally mandated step to acknowledge patient rights to either refuse or accept treatment (Omnibus Budget Reconciliation Act, 1990). It mandates the following:

- To provide written information to all adults concerning their right under state law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives. (The patient is to receive this information at the time of admission to a hospital, a skilled nursing facility, a home health agency, or a hospice program.)
- To document in the individual's medical record whether or not the individual has executed an advance directive.
- Not to condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive.
- To provide for staff and community education for issues concerning advance directives.

It was thought the PSDA would not only increase the power of consumers, but also provide a mechanism for controlling health care costs, enhance the potential for beneficence as defined by the patient, and correct the balance between health care consumers and providers (Rouse, 1991). Following the American Hospital Association’s Patient Bill of Rights of 1970, the PSDA seemed to be the next logical step toward patient autonomy. In addition to the Federal government, the Joint Commission on Accreditation of Healthcare Organizations also required patients be involved in treatment decisions.

**FORMS OF ADVANCE DIRECTIVES**

The most common form of an advance directive is the living will. The patient must be competent to execute a living will and is not required to have medical or legal guidance. This sometimes makes living wills difficult to interpret and too inflexible for individualized direction of care.

Another form of an advance directive is a durable power of attorney for health care (DPAHC). With this type of directive, individuals appoint a proxy who will make health care decisions for the individuals when they become incompetent. In most states, the patient must be terminally ill or in a persistent vegetative state for the DPAHC to become effective, but some states do not stipulate this requirement.

A study conducted in an outpatient geriatric clinic in New York found that proxy appointment, rather than living wills, may be an easier concept both for doctors to present and for patients to understand (Meier et al., 1996). However, according to Sansone and Phillips (1995), the DPAHC has limited effect on life support decisions because the decision-maker may not know what treatments the patient would prefer. Further, in some instances the ethical and psychological burdens are so overwhelming that surrogate decision-makers are unable to make decisions that would allow a person to die. For these reasons, many individuals suggest a combination of the two—a living will and a DPAHC. This is reflected in the advance directive forms of most states, which include both a living will and a proxy decision-maker.

There are two other forms of advance directives that are not well known. One is a comprehensive advance medical care directive, in which precise instructions are given related to the type of care that is wanted or not wanted, depending on

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the various scenarios (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991). The other is called a values history (Doukas & McCullough, 1991). This survey document is not legally recognized, but is intended as a supplement to the living will and DPAHC. The values history can be helpful in interpretational issues, but it is lengthy and may be confusing or ambiguous.

LITERATURE REVIEW

A review of the literature provides an overall view of the history of advance directives. The studies in this review cover a period from 1986 to 2000 but are limited because of space restrictions. (An extensive bibliography is available from the author.) This includes time frames both before and after the enactment of the PSDA in 1990. (Although this act was passed in 1990 it did not go into effect until December 1, 1991.) The research on end-of-life decision-making conducted prior to the PSDA was initiated in the mid-to late-1980s, even though the concept of a living will was developed in the late 1960s. During that 20-year gap, the landmark cases of Karen Quinlan and Nancy Cruzan were brought to the public’s attention. It is from this history that advance directives were created.

The research studies in this review have been categorized into a specific content area, though many of these studies had multiple areas of concern and could have been included in a variety of content categories. The content areas included for the purposes of this review are:

- Who executes an advance directive?
- What are the preferences underlying the choices made in the advance directive and how stable are these choices?
- What can be done to increase the number of advance directives?
- Who discusses advance care planning with patients and what is the nature of the discussion?

- How do advance directives affect the treatment?
- How do advance directives affect the individuals who draft them?
- How are advance directives promoted within the health care system?

Categories address professional and patient education, as well as education for surrogate decision-makers.

Current data suggest 3 to 6 million individuals in the United States are incapacitated because of substantial dementia (Lynn & Teno, 1995). This does not take into account numerous others who are incapacitated because of cerebral vascular accidents, brain tumors, or brain trauma resulting from accidents, for example. The decisions made for these individuals come from their preferences explicat-ed before decisional incapacity occurred, from surrogates, or from community and professional guidelines.

The ideal, however, is to make decisions based on an individual’s explicit wishes. Advance directives are relevant for this purpose because they have bearing on, or are committed to, the matter at hand. They address the explicit wishes of individuals regarding treatment decisions when they cannot give informed consent.

WHO EXECUTES ADVANCE DIRECTIVES?

Studies concerning the characteristics of individuals executing advance directives often addressed the disease state present at the time of the advance directive discussion. The researchers studied the effect specific disease processes or illness in general had on the completion of advance directives. Included in the studies were:

- Individuals with mental illness (Backlar & McFarland, 1996).
- Individuals with renal disease requiring dialysis (Cohen, McCue, Germain, & Woods, 1997).
- Individuals receiving pulmonary rehabilitation (Heffner, Fahy, & Barbieri, 1996).
- Individuals receiving cardiac rehabilitation (Heffner & Barbieri, 1996).

- Individuals who presented in the emergency department (Ishihara, Wrenn, Wright, Socha, & Cross, 1996).
- Individuals with questionable decision-making capacity (Ganzini, Lee, Heintz, Bloom, & Penn, 1994).
- Individuals with amyotrophic lateral sclerosis (Moss et al., 1996).
- Individuals with AIDS (Gilban, Kumar, deCaprariis, Olivieri, & Ho, 1996).
- Individuals admitted to a hospice (Schonwetter, Walker, & Robinson, 1995).
- Individuals admitted to a hospital (Silverman, Tuma, Schaeffer, & Singh, 1995).
- Individuals who were seriously ill (Support Principle Investigators, 1995).
- Individuals in an outpatient Veterans Affairs setting (Sugarmann, Weinberger, & Samsa, 1992).

The results of the cited studies indicated that advance directives were considered important by the majority of both the well and ill populations, but not many advance directives were actually executed.

Also included were studies in which ethnicity was a factor in advance directive completion (Hauser, Kleefield, Brennan, & Fischbach, 1997). These studies advocated culturally sensitive advance directives to meet the significant ethnic differences in health care choices. General characteristics associated with advance care planning have also been described (Emanuel, Weinberg, Golin, Hummel, & Emanuel, 1993; Leslie & Badzek, 1996). These studies generally concluded that advance directives have not been an effective means to elicit patient preferences. Thus, health care providers may need to consider other mechanisms to define these preferences.

“The aging of the population and the wide availability of advanced medical technology has led, almost inevitably, to increasing pressures to keep bodies alive longer than the quality of life can be maintained.”
according to Palker and Nettles-Carlson (1995, p. 7). Advance directives advocated by the PSDA are particularly useful for three types of patients. These are patients for whom a legally designated surrogate does not exist or is controversial, patients with highly specific or unusual preferences, and patients and families for whom the existence of a document will reduce anxiety (Marsden, 1992).

Shared decisions are usually good decisions. The PSDA fosters shared decision-making between the physician and the patient. This is both a benefit and a problem because there are no clear guidelines for how a physician should determine whether patients are capable of sharing in their medical decisions (Schneiderman, Teetzel, & Kalmanson, 1995).

What are the Preferences Expressed in Advance Directives and How Stable are the Choices?

The next category included studies in which an attempt was made to define the preferences that underlie executed advance directives and the stability of those choices after they were explicited. Researchers questioned the best way to obtain meaningful information related to patient advance directive preferences (Alpert, Hjortink, Fischer, & Emanuel, 1996). The medical directive, the life support preferences questionnaire, perceived scenarios, health states, and assessment of personal values were all used in these studies to illicit meaningful information from individuals related to advance care planning. The stability of choices that individuals made was moderately high during a 1 to 2 year period. Some of the studies showed that advance directive preferences were linked to knowledge about CPR, health status, and prognosis (Joos, Reuler, Powell, & Hickam, 1993). In the studies, physicians and nurses (Gillick, Hesse, & Mazzapica, 1993) and patients with AIDS (Steinbrook et al., 1986) were queried about their end-of-life preferences. Schneiderman, Kaplan, Rosenberg, and Teetzel (1997) concluded that physicians’ perceptions of what a patient would want matches what physicians would want for themselves.

What Can be Done to Increase the Number of Advance Directives?

Methods to increase the number of individuals drafting an advance directive were the subject of numerous studies. Most were related to advance directive education and the need for this education to be varied in location, format, and substance (Bailly & DePoy, 1995). These included videos; pamphlets; and discussions that were conducted prior to admission, were structured, or were ongoing. Videos did not significantly affect comprehension (Siegent, Clipp, Mulhausen, & Kochersberger, 1996). Discussions were repeatedly cited as beneficial to advance directive completion rates, as well as nurse and physician behaviors perceived as supportive by patients and families. Some found discussion or counseling beneficial (Brown, 1998; Hoffman & Gill, 2000).

An interesting concept from this group of studies addressed the issue of family planning—not just for births, but also for contemplated deaths (Foley, Miles, Brock, & Phillips, 1995). Access to assistance (Molloy et al., 1997) and making advance directive forms available (Vandecreek & Frankowski, 1996) were considered in many studies. One study did advocate waiting until admission to discuss the options available because the crisis of hospital admission acts as a stimulus for addressing these decisions.

According to Hesse (1995), “Conferences held at a time of acute illness might allow the family to see and experience the patient’s medical condition in a way no advance directive can portray and may result in decisions more appropriate to the patient’s best interests” (p. 1517). Most healthcare personnel promote the discussion and completion of advance directives prior to hospitalization in a planned setting, well in advance of life threatening illness (Klaas, 1995).

Only one study was found that addressed the readability of advance directives. Ott and Hardie (1997) applied the Flesch-Kincaid and Gunning’s Fog Index, two readability formulas, to 10 advance directive documents from various sources. They found that average readability was between 11.3 and 18.2 grade levels. Their recommendation was to refine advance directive documents for greater patient understanding.

This concept of readability is important not just for the advance directive document, but also for the informational materials provided for advance directive education. Weinrich and Boyd (1992) recommended a seventh-grade readability level for educational materials for elderly individuals. This was addressed in two studies in which an elder-sensitive brochure on advance directives was developed and tested (Husted et al., 1997; Husted, Miller, & Brown, 1999).

Because it is usually not sufficient to address only the length of sentences and the number of syllables per word, the print style and size, space between lines of text, use of illustrations, color, and paper texture are all factors which should be considered in the production and testing of this brochure. It should incorporate characteristics that make it friendly to older adults: using muted, quiet colors; non-shiny paper; bold, well-defined print; contrast between the print and the paper; and “catchy” headings (Husted et al., 1997).

These findings of the studies support this research. The studies stress the need for creative advance directive education and discussion, greater than that which was mandated by the PSDA, as a means of increasing the number of individuals with advance directives. Evidence suggested that patients participating in educational interventions that
included discussions were more likely to complete an advance directive (Mezey, Bottrell, Ramsey, the NICHE Faculty, 1996).

Another concept affecting whether or not an individual would draft an advance directive is motivation. Motivation is defined as a “set of processes that arouse, direct, and maintain human behavior toward attaining some goal” (Greenberg & Baron, 1995, p. 126). This is a key factor because success of the advance directive process depends on how well health care professionals motivate older adults to actually draft the document.

“If we believe that our behavior will affect the outcome, that we have control over the outcome, then we will respond differently than if we believe the outcome is due to chance or other people’s behavior,” according to Schaie and Willis (1991, p. 314). Drafting an advance directive is a behavior that allows individuals to have control over their end-of-life decisions—these decisions will not be caused by chance or another person’s behavior.

Age was the most important predictor of preferences about keeping, sharing, or giving away control. Older adults preferred less control (Degner & Sloan, 1992). Health care professionals could be seen as powerful others who should initiate the advance directive discussion. The fact that the health care professional was interested in discussing advance directives with elderly individuals could be a motivational factor eliciting advance directive execution, even in those whose locus of control is external.

An individual is also motivated by a need to affiliate, to associate with other people, and to feel loved (Quinn, 1995). The presence of a health care professional who is caring, has a positive attitude about advance directives, and is willing to assist with understanding and completing an advance directive can be a motivating factor in older adults’ execution of advance directives. Researchers investigating the influence of dialysis staff on patients formulating advance directives found completion of advance directives more prominently correlated with environmental factors than with personal demographic factors. These environmental factors included discussion between staff and patients and perception of staff being comfortable discussing advance directives with patients (Perry et al., 1995). Hence, participants can be affected by the characteristics of the researcher.

This need to affiliate might also motivate elderly individuals to draft advance directives simply to please the researcher. One should consider the Hawthorne effect in which the participants behave in a particular manner largely because they are aware they are part of a research study (Politi & Hungler, 1995). This does not necessarily conjure a negative connotation. If the participants who draft advance directives under these circumstances understand and are satisfied with the advance directive they executed, then this is a positive event.

The use of printed educational material along with personalized reinforcement of the content yielded better outcomes than the use of either written material or personalized teaching alone (Bernier, 1993). A nurse and advance directive information given to older adults via written materials and discussion may provide motivational pull and increase self-efficacy, a belief that individuals have the necessary knowledge or skills to achieve their goals. Thus, these motivational factors may prompt the execution of advance directives.

Who Discusses Advance Care with the Patient and What is the Nature of the Discussion?

Any advance directive process should include discussion. Important factors in the discussion process are who conducts the discussion and how it proceeds. In most of the research, physicians were the primary health care professionals responsible for these discussions (Emanuel et al., 1991). Studies were found in which nurses were the primary educators and advocates, and in a few studies in which social workers played the primary role (Littrell, Diwan, & Bryant, 1996; Luptak & Boul, 1994). Although one study showed that nurses’ understanding of patient CPR preferences was no better than physicians’ or surrogates’ (Puopolo et al., 1997), other studies highlighted the nurse as the primary educator and advocate who was neutral, compassionate, and available (Pinch, Miya, Boardman, Andrews, & Barr, 1995).

The nature of the advance directive discussion also is related to the context. There is concern that advance directives are misused by physicians and serve to limit, rather than preserve, patient autonomy (McIntyre, 1995). If the advance directive is an autonomous patient choice, then this autonomous choice presupposes the patient:

- Has decision-making capacity.
- Is not impaired by a variety of factors that interfere with autonomous choice.
- Receives information about the risks and benefits of options for care.
- Has the opportunity to question and receive answers in relation to issues involved in any decision (Oddi, 1994).

When autonomous choice is not possible, there is concern about who decides and who defines loss of decision-making capacity and ability to consent (Hardy, 1995; Schneiderman & Teetzel, 1995).

In advance directive discussion, it is necessary to ask questions to determine if the criteria for informed consent are present because there is almost always some question about the validity of the directive. These criteria include competence, disclosure of information, comprehension, and voluntariness (Cisar & Bell, 1995). It is also necessary to identify some of the key components of the directive. For example, is the directive signed, dated, and witnessed notarized?
Neutrality of the health care worker, how "impossible" choices are made, and the role of emotion in advance directive decisions were also considered. Peppin (1995) addressed the unattainability of value neutrality in end-of-life decisions. This lack of neutrality by health care profession- als can be attributed to ageism, a largely negative attitude toward older adults; limited resources and financial constraints; the influence of health care corporations; compassion; and quality of life standards frequently based on the ideals of young, healthy professionals and concepts of "futility" (Peppin, 1995).

Discussion related to end-of-life decisions often involves questions that require a discomforting choice. If the discomfort is sufficient, the individual may respond by using a reflexive response based on emotion rather than a rational process (Howe, 1995).

The ideal goal is for the individual to make an ethical decision in which emotion and reason are balanced (Callahan, 1988). There are those cases in which the question is not consent to treat, but consent not to treat, where the definition of futility plays a role in treatment decisions. Furthermore, included in the decision to treat or not to treat is the consideration that involves organ and tissue donation as part of the advance directive (Laskin, 1995).

How do Advance Directives Affect Treatment Decisions?

The research conducted to determine the effect of advance directives on medical treatment often used the do-not-resuscitate (DNR) order as a marker to establish whether or not advance directives were followed (Choudhry, Ma, Rasooly, & Singer, 1994). Other studies compared care given with care requested or refused in the individual's advance directive (Danis et al., 1991), and others addressed resuscitation efforts (Dull, Graves, Larsen, & Cummins, 1994). Withholding or withdrawing treatment were other markers used to evaluate the influence of advance directives on treatment (Faber-Langendoen, 1996).

Implementation problems can stem from advance directive interpretation, incompetent surrogates, last-minute oral statements made by the patient, surrogates who seem to be acting contrary to what rational desire would seem to indicate, and health care providers refusing to follow the advance directive (Husted & Husted, 1995). The social commitment of the physician is to sustain life and relieve suffering. If one conflicts with the other, the physician should follow the patient's wishes (Post, Peters, & Stahl, 1994).

The influence of advance directives on treatment depends on the way in which the advance directive is interpreted. "When physicians are presented with oral or written directives stating 'no machines' or 'DNR' they should clarify the specific meaning of the directive with the patient or the surrogate," according to Reiter (1995, p. 37). Reviewing the patient's advance directive on admission may clarify any contradictions that may be found between values assessed during the admission process and wishes expressed in the advance directive (Stubbs, 1995). This process of interpretation includes two elements: reconstructing the context of the text to determine the original, intended meaning and applying the originally intended meaning to the context of the current situation (Potter, 1995). It may mean, at times, a patient-centered model of medicine may be in competition with the traditional physician-centered model (Spike & Greenlaw, 1995).

To formulate any comprehensive advance directive, one must consider a wide range of mental states and infinite combinations of mental and physical dysfunction. Individuals drafting advance directives are required to consider many possible factors about remote, abstract events. In addition, patient's feelings may change with time and the presence of illness. Therefore, as stated by Campbell (1995), "Clinicians have the obligation to provide surrogates with guidance to ensure sensible interpretation of the directive in a particular clinical context" (p. 231). This is one of the reasons so much controversy is related to the appropriate time and place for the advance directive to be completed. The PSDA dictates that federally funded health care institutions inform all patients on admission about their rights under state law to participate in decisions related to their health care, including the right to make advance directives. There is concern that patients are unable to absorb this information at the time of admission (Navarre, 1995) or immediately prior to surgery (Huth, 1995).

How do Advance Directives Affect the Individuals Who Draft Them?

There has been a concern about the effect of advance directive discussions on the patients' sense of well-being (Kellog, Crain, Corwin, & Brickner, 1992; Palker & Nettles-Carlson, 1995). Study results have indicated that anxiety attributable to these discussions is low. Rather, individuals welcomed the opportunity to discuss end-of-life care. A qualitative study with surrogate decision-makers supported advance directives as a means to protect patient autonomy, thereby assisting the family with long-term acceptance of the experience and the decisions (Jocoh, 1998).

According to Cantor,

Advance directives emerged as a vehicle for people to control post competence medical intervention in a dying process. The object is to permit individuals to prescribe personal preferences in advance directives and so to maintain a measure of autonomy even after incompetency (1993, p. 23).

Advance directives are beneficial because they reduce anxiety, increase self-respect, and save public resources. However, gray areas exist. For example, are health care professionals only addressing patients in
the terminal end-stage? What about patients who are stable but severely debilitated? Will their autonomy be respected regardless of how long their lives are preserved?

**How are Advance Directives Promoted within the Health Care System?**

The need for professional advance directive education across all disciplines (Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996), especially for nurses (Barta & Neighbors, 1993) and physicians (Gordon & Tolle, 1991), was explicated in many studies. The need for patient education to be available (Heffner, Faby, Hilling, & Barbieri, 1997; Singer, Choudhry, & Armstrong, 1993) and to use culturally sensitive educational materials (Gates, Schins, & Smith, 1996; Hepburn & Reed, 1995) was also addressed. Rapidly expanding technologies in health care have increased the complexity of health care decision-making. Signed into law 5 months after the 1990 Cruzan Supreme Court decision, the PSDA was to focus on policies and practices to maintain patient dignity, stimulate effective teamwork, and honor the health care professionals’ moral beliefs (Purtill, 1991). However, the PSDA had no precise implementation requirements.

One of the major problems of PSDA implementation is no provisions for funding were made. Without funding, there is no creative implementation, and unless a regulation is supposed to save money, little is done to monitor it. Translating the public policy of the PSDA into meaningful decision-making requires funds (Gill, 1993).

The heart of any strategy designed to address patient choice in medical decision-making is education and effective communication, keeping in mind the difference between public awareness and public education. Implementation of the PSDA in health care settings addressed institutional protocols that were supposed to assist staff in making rational, consistent decisions related to patient care in the face of complex issues and relationships. The protocols were to address how decisions are made and the policy conducted without involvement of the substance or outcome of the decision. Organizations and providers have found it necessary to comply with the letter and intent of the law (Gill, 1995).

Some facilities have used their admitting departments to assure and document technical compliance. Present implementation of the PSDA is an event dominated by brochures and forms (Wolf, 1991). Although compliance with advance directives is audited periodically (Callahan, 1991), there is no payment for services and no authorization. Complaints can be filed, litigation threatened, and internal ethics committees convened; however, there is really no method of enforcement. In other facilities, nurses are responsible for implementing the PSDA, but they have an unclear authority about their role in discussing advance directives (Mezey, Evans, Golub, Murphy, & White, 1994). In some facilities, the physician initiates and participates in advance directive discussion with the patient.

More than mere paper compliance is needed. Institutions are legally responsible for informing the patients. This requires collaborative efforts by health care providers. Nursing can take a leading role in this effort. Nurses assess and evaluate changes in the patient’s perspective and health state and, thus, facilitate decision-making (American Nurses Association [ANA], 1991). A health care planning nurse in a clinic may be in a position to provide another avenue for PSDA implementation (Emanuel, 1991).

The crucial ingredient to the task is not the written materials and orders, but the nurses (Gill, 1993). Many nurses perceive it as their role to promote discussion of advance directives, but they need to be given the education, time, and institutional support to achieve this goal. The American Association of Critical-Care Nurses (AACN) has undertaken a multilevel program, “Helping People Make Care Choices” (1995), in response to recommendation from the AACN and the Annenberg Working Group (1993). This program provides nurses with information about advance directives so they can educate consumers. The ANA position statement advocates nurse involvement (Gobis, 1992). Nurses can help patients understand what health care treatments are likely to be considered based on their health history (“Nurses Can Provide Insight,” 1995). There is evidence that PSDA program implementation has provided the impetus for health care workers not only to assist patients, but also to examine their own wishes concerning treatment decisions (Barnett & Pierson, 1994).

If a more responsive health care system is to be attained, a system based on the needs of all patients is required (Chulay, 1993). The issue of advance directives has been addressed by varied disciplines in various fields as an effort to do just that. The PSDA is one of many steps needed to move to a more patient-centered health care system.

Physician assistants described their role as direct caregivers and liaisons between the patient and the physician, and thus, are in a unique position to provide guidance and patient education and ensure compliance of advance directives (Kelley, 1995). Emergency medical personnel have also recognized the effect of advance directives. States are currently dealing with DNR protocols in the community in an attempt to give emergency responders resuscitation guidelines (Cragin, 1995).

In some instances, there is confusion and lack of clarity among health care providers and consumers about the differences between euthanasia, assisted suicide, and cessation of treatment (Erickson, Rodney, &
providers have no knowledge about what care elderly individuals would want and no one is available to provide this information. "About 30% of elders do not have a relative or friend who can make care decisions for them," according to Mezey et al. (1996, p. 204). Health care professionals, especially nurses, are in a position to improve end-of-life care for older adults by helping them understand advance directives and execute them if they wish to do so before they lose their decision-making capacity.

**SIGNIFICANCE**

Only half of all individuals have estate wills. This may also be the upper limit for the number of individuals drafting advance directives. Simply requiring hospitals to provide written information is unlikely to activate patients to formulate advance directives (Sehgal et al., 1992). Advance directives should be seen as a process rather than an event. They should be part of the clinical process—not an administrative process to be carried out by an admissions clerk (LaPuma, Orentlicher, & Moss, 1991). If a patient makes a decision about the advance directive at the time of admission, they may make choices based on "the immediacy of their pain, discomfort, fears, and the press of time" (Cate & Gill, 1991, p. 23).

There are many unresolved issues related to the PSDA. The health care community and public support advance directives, but few actually complete a living will or DPAHC. It may be that health care professionals should not concentrate on getting more directives signed but, instead, use advance directives to invite discussion. Health care professionals should be asking questions about the patient's expectations and goals of care, how closely they want their advance directives followed, and what factors they want considered in decisions made for them.

**Significance for Health Care**

Legal and ethical systems have not kept pace with technological advances (Catalano, 1994). The PSDA, which results in patients having vital information about end-of-life care, is relevant because it begins to address the problem between life sustaining technology and the natural end of a person's life—but it is not enough. The right to self-determination, as indicated by informed consent, is ethically based on the standards of autonomy, freedom, privacy, objectivity, beneficence, and fidelity (Husted & Husted, 1995). The intention is an ethical one, but the PSDA is not without problems. Communication and discussion are needed among health care professionals and patients (Cox & Sachs, 1994).

The effect of the PSDA on advance care planning and patient autonomy has been disappointing. Depending on the literature cited, only 4% to 24% or 15% to 25% of adults have signed living wills (Cantor, 1993). The PSDA has not improved the process for the patient; the law is widely circumvented and misapplied.

The use of formal advance directives has not significantly increased, nor has the frequency of discussion between patients and physicians, or specific treatment discussions between patients and their proxies. Even with education, elderly individuals are not executing advance directives (High, 1993). The PSDA has increased patient awareness of living wills, but has not increased the number of individuals who act on this awareness (Robinson, Dehaven, & Koch, 1993).

Patients are not necessarily offered assistance in preparing advance directives. Because they are not obliged to execute advance directives, their wishes may go unrecorded and unrecognized (Griffin, 1992). The PSDA initiated changes, but the attitudes of those providing the care must also change. "Medical literature suggests that advance directives com-
pleted under the Act’s auspices have little impact in the clinical setting and that many health care providers acknowledge over-treating terminally ill patients and ignoring their wishes,” according to Minnow (1993, p. 3).

“Simple educational interventions, like those mandated by the PSDA, are unlikely to increase patients completion of durable health care proxies” (Reilly et al., 1995, p. 2202).

Solutions to the problem are most frequently centered on improving communication between patients and health care providers (Curtin, 1996; Richter et al., 1995). However, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (Support Principle Investigators, 1995) concluded that enhancing opportunities for more frequent patient-physician communication, may not, in and of itself, be the answer to changing established practices. If the number of advance directives was increased, further significance to health care might be realized in decreased costs, increased appropriate use of resources, and increased patient autonomy.

Significance for Nursing

Problems have been identified in previous advance directive research concerning the best setting in which to share advance directive information, the best method by which to provide this information to patients, the content of advance directive educational material, and the best person to facilitate this process. Silverman et al. (1995) believe nurse implementation of the PSDA is appropriate. This is because nurses have the primary responsibility for helping patients maintain or regain their identity. Nurses know the interpretational problems that can arise and can help the patient understand difficult terminology because reading skills greater than sixth grade, at the very least, are necessary for understanding advance directive brochures (Otten & Hardie, 1997; Weinrich & Boyd, 1992). Also, nurses can help patients weigh their personal values against various treatment choices.

Spurred by the effect of evaluation data and the need to provide direction in the PSDA process, the AACN and the Annenberg Washington Program in Communication Policy Studies of Northwestern University convened a working group in 1992. This work group examined the principles of public information, education, and communication as they relate to the PSDA. They also examined the current education models developed to implement the PSDA, and defined educational and community strategies to facilitate implementation of the PSDA.

Their recommendations are as valid today as they were then. They call for action, beyond the legal mandates, to move from the clinical setting to a less threatening environment, and to reach individuals who do not have contact with health care institutions. Advance directives need to be approached from the individual’s point of view and each individual must be given accurate, relevant, and understandable information taking into account personal sensitivities and needs.

Nurses, by their defined role, are educators and advocates, thus they are also educators and advocates in the dissemination of advance directives. Nurses are in a position to provide support and information, and make referrals related to end-of-life decisions. Further, patients are comfortable with nurses inquiring about advance directives (Emanuel, 1993), and nurses often spend more time with patients and family members than physicians do (Baggs, 1993). “The PSDA simply standardizes and formalizes conversations that nurses customarily had with their patients,” according to DesRosiers and Navin (1997, p. 127).

REFERENCES


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