Facing Reduced Decision-Making Capacity in Health Care: Methods for Maintaining Client Self-Determination

Barbara L. Nicholson and Gerald N. Matross

Recent advances in medical technology have improved life-sustaining treatment methods for terminally ill and comatose patients. Individuals now are able to live beyond their capacity to maintain self-determination and their ability to make autonomous decisions. This situation presents difficulties for many patients, such as the elderly and those with advanced cases of acquired immune deficiency syndrome. The ethical base of the social work profession is a commitment to enhancing individual self-determination. But how can self-determination be maintained when clients are unable to make autonomous health care decisions because they are suffering from a terminal illness, are unconscious, or are in great pain? A review of the social work literature indicates that there has been little discussion of this topic.

The focus here is an illustration of methods by which professional social workers can empower clients to maintain a degree of self-determination if they become incapable of making their own decisions regarding medical treatment. The concepts of competency and incompetency are clarified and various forms of advance directives, including durable powers of attorney, living wills, and oral communications, are explained. Additionally, the issues raised in attempting to determine the best interest of patients whose health status has rendered them unable to participate in discussions about their desired medical treatment are explored and theory is applied to case material to illustrate methods for social workers to enhance self-determination for their clients.

Self-determination refers to the basic right of all individuals to act in accordance with their own values, goals, and personal choices. The National Association of Social Workers (NASW, 1980) Code of Ethics states that “the social worker should make every effort to foster maximum self-determination on the part of their clients” (p. 5). Thus, the concept of self-determination is an integral part of the profession’s value base. As Reamer (1983) stated, the value of self-determination “has become firmly entrenched in the profession’s collective psyche. To deny this concept is to challenge the integrity of one of the most permanent and secure pillars upon which social work is built” (p. 254).

Helping patients make life and death decisions, including whether to continue or to forego life-sustaining treatment, has become central to the social worker’s mission in the health care setting (Abramson & Black, 1985; Gelman, 1986; Holden, 1980; Holmes, 1980; Reamer, 1985). Social workers also have become involved in institutional ethics committees that recommend policies and act as consultants in matters of life or death.

Because of their specialized training, “holistic perspective, and scope of responsibility” (Gelman, 1986, p. 123), social workers are in a unique position to educate, counsel, and empower clients and their families. Social workers frequently have quantitatively more and qualitatively different kinds of interactions with their clients than do other health care professionals (Holmes, 1980). They are often the only professionals who are involved with patients and families from the beginning to the end of treatment. As a result, social workers may be in the best position to help patients become aware of the religious, ethical, and emotional values that influence decision making.

One responsibility of social workers is to facilitate client understanding of specific medical interventions and their consequences and of the various advance directives that will enhance self-determination. Social workers should be prepared to educate and counsel clients and their families about the specific options available to them and to assist them, if necessary, in procuring legal forms and/or attorneys.

Competent Adult Patient

Competency can be defined broadly as an individual’s capacity to understand and appreciate the nature and consequences of his or her actions. The NASW (1980) Code of Ethics and the President’s Commission for the Study of Ethical Problems in Medicine and Bioethics and Behavioral Research (1983) defend the competent person’s right to make decisions regarding specific medical procedures and overall treatment. The ethical principle of autonomy and the social work value of self-determination underlie this position.

Competent patients are mandated legally to give informed voluntary consent before any medical procedure is performed and after its risks and benefits have been explained. The legal right of a competent person to refuse lifesaving treatment is based on the ruling of Supreme Court Justice Benjamin Cardozo that “every human being of adult years of sound mind has a right to determine what shall be done with his own body” (Schloendorff v. Society of New York Hospitals, 1914). Thus, the courts have upheld a competent person’s right to forego treatment or even cure, if it entails what for him are intolerable consequences or risks, however unwise his sense of values may be in the eyes of the medical profession. (Canterbury v. Spence, 1972)

The ethical principle of autonomy and the legal tenet of informed consent prohibit forcing competent patients to undergo any treatment against their will, even for their own good.

Information about one’s medical condition does not determine by itself whether a procedure should be initiated. Religious
beliefs, values, and personal goals often are essential factors in decisions concerning specific medical treatment. Does the client want to live regardless of a grave medical condition, high levels of pain, or low levels of consciousness; or would death be preferable when there is no hope for a "meaningful life?"

Because social workers are committed to self-determination, they also are committed to helping their clients reach decisions based on the client’s values, goals, and conception of a meaningful life. Social workers should support the client’s final decision. This support will enhance and uphold the client’s right to self-determination.

Incompetent Adult Patient

A court hearing is necessary to establish whether an individual is competent legally to exercise the right to self-determination. As many as seven criteria have been employed to determine medical competency; to date, there is no standard definition or statutory consistency in the law (Chell, 1988).

A patient always should be assumed to be competent until demonstrated otherwise. Social workers must be aware of the importance of declaring a patient medically incompetent. Once such a decision is made, a patient loses the right to make many, if not all, significant medical decisions, and people other than the patient, usually family members or physicians, make these decisions.

Because establishing legal incompetency is often lengthy and costly, the lesser determination of decisional incapacity—the inability to make autonomous decisions about one’s own health care—may be acceptable in many cases. The President’s Commission (1982) defines decision-making capacity as: “(1) possession of a set of values and goals; (2) the ability to communicate and understand information; and (3) the ability to reason and to deliberate about one’s choices” (pp. 56-57). The failure to meet one or more of these criteria results in a patient being judged decisionally incapacitated.

The determination of whether a patient meets the criteria does not involve a formal court hearing, does not question the state’s presumption of an individual’s competency, and can be decided at the patient’s bedside. For example, “a patient may not have the decisional capacity to consent to renal dialysis due to temporary disorientation or confusion or intermittent dementia, yet a court determination of incompetency or disability would not be required” (High, 1987, p. 815). This informal method often is used when agreement exists among family members and health care providers about the best interest of the patient. Because these determinations are made extrajudicially, their legal status is uncertain. However, the practice is widespread and has been endorsed by the President’s Commission.

Questions of competency may arise when patients' decisions are incompatible with what others think is in the patient’s best interest. However, questions rarely arise when decisions are in accord with the values of the medical staff, families, lovers, or friends. However, the distinction between disagreement with a patient’s choice and the designation of incompetency is a crucial one. The decision to forego lifesaving treatment is not, in itself, a sign of incompetency or decisional incapacity. For health care professionals and families, it often is easier to question a patient’s competency than to recognize a legitimate conflict of values.

Advance Directives

Advance directives are a patient’s instructions for acceptable and unacceptable medical interventions. These directives become operative when a patient is no longer capable of conscious decision making and help to maintain patient self-determination over medical decisions after a patient has been judged to have limited capacity to make autonomous decisions or to be incompetent. An advance directive helps a surrogate (a family member, lover, close friend, or physician) determine what the patient would have wanted if he or she were able to make a decision autonomously.

Although advance directives can be advantageous, they do present several problems. Research studies have indicated that advance directives are employed infrequently; one study showed that only 6 percent of elderly or chronically ill patients had discussed their preferences for life-sustaining treatment with their physicians, even though over two thirds wanted such discussions” (Lo, 1988, p. 212). Further difficulties arise from directives that are either too vague (“I don’t want heroic treatment”) or too specific (“Under no circumstances should any surgical procedures be performed on me if I become unconscious”); furthermore, patients often are not sufficiently informed to understand treatments and their consequences.

The difficulties often can be resolved through education and increased communication among patients, physicians, and social workers. Social workers should encourage patients to discuss life-sustaining treatment. By doing so, social workers enable patients to decide in accordance to their own directives. However, directives should be sufficiently flexible to ensure that those carrying them out are able to respond to all medical situations that may arise. Advance directives may be informal, such as discussions with family, lovers, friends, and health care providers. However, patients’ demands for legal guarantees and physicians’ fears of legal liability have led to the enactment of more formalized advanced directives (Lo, 1988).

Living Wills

Living wills, or natural-death acts, typically permit a competent person to specify that no life-sustaining procedures that would artificially prolong the dying process will be used. Thirty-eight states and the District of Columbia have passed living will legislation, but no two statutes are identical. Key terms, such as "life-sustaining procedures" and "terminal conditions," are not commonly defined. Procedures and requirements for the enactment and implementation of living wills vary substantially from state to
state. Additionally, statutes are inconsistent regarding the kinds of medical interventions that can be withheld legally. For example, some statutes explicitly state that artificial nutrition and hydration may be withheld; others explicitly prohibit their exclusion (Society for the Right to Die, 1987).

Living wills are not without their shortcomings. A physician does not always know whether a condition is terminal or when death is imminent. Living will statutes are only valid when a patient is in a terminal state and are invalid for nonterminal conditions such as advanced Alzheimer’s disease or permanent vegetative states.

When patients cannot participate actively and directly in treatment decisions, some people have argued that previous advance directives may be overruled “on a finding that the patient did not adequately envision and consider the particular situation within which the actual medical decision must be made” (President’s Commission, 1983, p. 137). The California Natural Death Act of 1976, the first living will legislation, attempts to deal with this difficulty. The statute requires that a directive executed before a terminal diagnosis should be only advisory. The advance directive does not become binding until signed by a “fully competent [patient] not overwhelmed by disease or the effects of treatment,” at least 14 days after diagnosis (President’s Commission, 1983, p. 142). These requirements significantly undermine the intent of a living will. An economic will is not considered advisory until a person faces death and is only made binding after reconsideration. Why should living wills differ?

Despite the difficulties, the writing of a living will provides an opportunity for patients to discuss their wishes with family, physicians, and/or social workers. The living will also provides a catalyst for patients to think through their goals, values, and perceptions about what constitutes a meaningful life. If social workers encourage patients to write living wills, patients then can retain some control over future medical decisions.

Power-of-Attorney Statutes

Durable power-of-attorney statutes have fewer limitations than living wills. They authorize an individual (attorney-in-fact) to make decisions on behalf of a patient who no longer is able to make medical decisions. The attorney-in-fact is designated before the patient becomes unable to make decisions autonomously, and bases his or her decisions on the patient’s previously stated wishes.

Traditional power-of-attorney statutes authorize an attorney-in-fact to conduct business on a person’s behalf (for instance, selling a car). This authority disappears if the person dies or becomes incompetent. A durable power of attorney becomes effective or remains effective, depending on how the document is written, after the person has become incompetent (Clarke, 1988). Durable power-of-attorney statutes that deal with economic and other personal matters also have been interpreted to apply to health care decisions (President’s Commission, 1983). Several states, such as California, Pennsylvania, and Colorado, have begun to pass laws that define power of attorney and are aimed explicitly at health care issues.

Durable power-of-attorney statutes are broader in scope and more powerful than are living wills. They authorize the attorney-in-fact to make all health care decisions as if he or she were the patient. Legal authority involves both giving and withholding consent for all medical procedures and is not contingent on the patient’s being in terminal condition. The attorney-in-fact has access to medical records and the authority to disclose these records, and can authorize the expenditure of funds for the patient’s medical care.

Substituted Judgment

When a previously competent patient becomes incompetent to make medical decisions, either a “substituted” or “subjective” judgment may be made by family and physicians if no living will or durable power of attorney exists. Health care providers, including nurses and physicians, and social workers, gather previous communications and actions that reflect what the patient would have wanted (“substituted”). From this information, a judgment is made that reflects the inferred wishes of a patient (“subjective”). The judgment does not necessarily reflect the patient’s objective best interest but does respect the patient’s right to self-determination.

If a previously competent patient has neither a living will nor a durable power of attorney, more inference is required to determine his or her wishes. Such inferences are controversial, as recent court decisions illustrate.

Brother Fox, an 83-year-old member of a Roman Catholic religious order, suffered a heart attack during an operation. Subsequently, he lapsed into a permanent vegetative state. Brother Fox had previously discussed his theological and moral feelings about terminal care with members of his religious community. He clearly stated that he would not want to be kept alive on a respirator if he were in a permanent coma, and he repeated the desire 2 months before he became ill. His guardian requested that Brother Fox’s respirator be removed (Eichner v. Dillon, 1981). The request was granted; Brother Fox’s wish and his right to self-determination were respected.

The New Jersey Supreme Court judged Karen Quinlan’s advance directives as more ambiguous, although her medical situation was similar to that of Brother Fox. At age 21, Quinlan went into a coma. She had told her mother on three occasions that she would rather die than be kept alive on machines. Quinlan also had told a friend that “she would not want to be kept alive by such extraordinary means, under any circumstances” (In re Quinlan, 1976). Her father petitioned that her respirator be removed and that she be allowed to die.

In 1976, the court did not recognize Quinlan’s statements as indicative of a valid choice. They were judged “remote and impersonal.” In this case, her right to self-determination was not respected. The same court, in the 1985 Claire Conroy case, noted that it had erred in “disregarding evidence of statements that Ms. Quinlan made to friends concerning artificial prolongation of lives of those who were terminally ill” (In re Conroy, 1985). The Quinlan case illustrates the necessity for explicit, legally binding advance directives.

The case of Earl Spring demonstrates the difficulty in determining an incompetent patient’s treatment preferences when the patient’s desires have not been
made clear. The wife and son of this 78-year-old senile patient sought court approval to remove him from kidney dialysis. The wife argued that her husband would “not want to live like this” because he had been an active, decisive individual who enjoyed outdoor activities (In re Spring, 1980). But how compelling is this argument? Being an active and decisive individual could be equally compatible with a desire to have medical treatment that could prolong life. Lack of information made it difficult to interpret Spring’s desires.

The Joseph Saikewicz case is an example of a patient who was never competent (Superintendent of Belchertown v. Saikewicz, 1977). Saikewicz was a 67-year-old man with an intelligence quotient of 10 who had lived his entire life in a state institution. A decision had to be made as to whether to continue Saikewicz’s painful chemotherapy treatment, which offered a 30 to 50 percent chance of remission for 2 to 12 months. His two sisters, who had not seen him for 63 years, were unwilling to become involved.

Who should make this important decision, and on what basis? The emerging consensus is that a court-appointed guardian should try to determine in an objective manner what is in the patient’s best interest. Because there is no indication of what such a patient would decide autonomously, decisions should promote the patient’s best interest as “conceived by a reasonable person in the patient’s circumstances” (President’s Commission, 1983, p. 136).

Best Interest Criterion

Claire Conroy, an 83-year-old woman, was unable to move from a semifetal position; she suffered from progressive senile dementia. She had numerous other medical problems, which ranged from a heart condition and diabetes to an inability to control her bowels, speak, or swallow. In a precedent-setting decision, the New Jersey Supreme Court applied what it called the “pure objective” test; that is, the court decided that medical care can be withdrawn if “the net burdens of the patient’s life with treatment clearly and markedly outweigh the benefits that the patient derives from life so that recurring, unavoidable, and severe pain of the patient’s life with the treatment would render the life-sustaining treatment inhumane” (In re Conroy, 1985, p. 321). One of the justices dissented, arguing that other human values, such as independence, privacy, and dignity, are neglected or outweighed when pain is the only source for the determination of best interest.

American society experiences a diversity of values. How can any objective measure weigh both the burdens and the benefits necessary to make decisions about what is in the best interest of a patient, when “reasonable persons” have different ideas about what the best interest is? Some believe that the relief of pain is paramount, and others embrace vitalism, the view that human biological life is always meaningful and must be preserved regardless of pain or degree of consciousness. Still others argue that life-sustaining treatment is in the best interest of the patient only if he or she has the capacity to experience the care and love of others. Another view supports the argument that treatment is not required if the patient has lost the capacity for autonomous living (Emanuel, 1987).

These perspectives illustrate the difficulty in reaching a consensus when sufficient information is lacking and someone else’s values must be imposed on the patient. To avoid such situations, social workers should encourage clients to think about these issues and to discuss them with their families and with their physicians.

Educating Clients about Advance Directives

The role of social workers is essential to the promotion and maintenance of client self-determination. The NASW (1980) Code of Ethics, however, specifies other values that sometimes conflict with those of self-determination, such as the social worker’s responsibilities to colleagues, employers, and society. In addition, social workers may experience conflict between patient autonomy and paternalism (Abramson, 1985; Reamer, 1983). Space limitations have precluded a discussion or a resolution of such ethical dilemmas here.

When decisions about medical treatment in life-or-death situations must be made, self-determination can be maintained best when clients communicate their treatment preferences while their ability to make autonomous choices is still intact. A clear articulation of advance directives will enhance and promote self-determination.

A written document that spells out both personal values and specific instructions will help ensure that a patient’s wishes regarding medical treatment will be carried out. Advance directives in the form of durable powers of attorney provide the greatest assurance that treatment preferences will be respected. Other types of directives including living wills, written statements, and oral communications with family and physicians before and during a life-threatening illness, when the patient is still capable of making independent decisions. Inferences based on past statements and behaviors of the patient are the most problematic.

Social workers have a responsibility to understand clearly the strengths and weaknesses of the various forms of advance directives so that they can provide education and counseling for their clients. Clients then will be able to make informed decisions about which of the various options will maximize self-determination and personal autonomy.

Social workers also counsel and educate patients and families about their specific needs and desires. They are a catalyst for the discussion of individual values, circumstances, and life-styles. These factors must be assessed and discussed before a sound decision about a patient’s treatment can be made.

When counseling families of patients who are unable to make their own decisions and who have not explicitly stated their treatment preferences, social workers must help the family to make inferences about what the patient would have wanted. When there are few explicit guidelines to follow, value conflicts and confusion for both social workers and families are to be expected. Inferential data can lead to uncertainty. Decisions that appear to represent the patient’s wishes may be based on the subjective interpretations and values of the decision makers. Thus, social workers must help others to become aware of these difficulties and must develop a high level of
self-determination consciously and self-awareness so that their own value biases do not interfere with their capacity to distinguish best interest criteria from patient self-determination. Self-determination is not maintained when clients’ ability for autonomous decision making is significantly reduced. Therefore, social workers involved in medical treatment planning for clients unable to make medical treatment decisions for themselves must protect client self-determination consciously and consistently.

When advance directives are lacking, it may be impossible to determine the patient’s wishes objectively. Therefore, an appeal to the best interest criterion must be made. Veatch (1984) has argued that, within certain parameters, the family should make such decisions based on their own values. However, this would not resolve the problem for patients who are unable to make their own decisions and who are without family involvement.

These clarifications illustrate the importance of planning for the future with patients to ensure that their treatment preferences will be respected. However, advance directives are not synonymous with self-determination. Patients and families must realize that health care providers may view advance directives simply as guides for determining and respecting patient choices rather than as instructions to be followed specifically and absolutely (Van Allen, 1988).

References


In re Quinlan, 70 N.J. 10, 335 A. 2d 645 (1976).

Accepted March 10, 1989