
119. Surrogate Decision Making

Introduction

At the 1991 Annual Meeting, the American Medical Association adopted the report of the Council on Ethical and Judicial Affairs, “Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients.” The recommendations of the report were the basis for amendments to Opinion 2.20, “Withholding or Withdrawing Life-Sustaining Medical Treatment.” The report itself provides guidelines for physicians who may have to identify a surrogate decision maker, assist a surrogate or proxy in making decisions for incompetent patients, and resolve conflicts that may arise between decision makers, or between the decision maker’s choice and medically appropriate options. Since the incorporation of these guidelines into the AMA’s *Code of Medical Ethics*, the Council has deferred to Opinion 2.20 to address inquiries involving surrogate decision making, even though the guidelines presented in this Opinion refer only to decisions made near the end of life.

With continued discussion concerning health care preferences for all patients, including those who are incompetent, and greater options available to secure health care directives, the involvement of third parties in a patient’s health becomes more likely in decisions that may occur in instances other than the end of life.

In addition, the Council recognizes that there is a spectrum of decision-making capacity ranging from immaturity, to mental illness, to serious brain damage, and that health care decisions often must be made for individuals with diminished decisional faculties over extended periods of time. The Council offers the following report to expand on its previous guidelines and to identify features related to a meaningful and effective physician-proxy relationship.

The report begins by defining a number of terms related to health care directives before presenting theoretical frameworks used in making decisions for incompetent patients. It then provides a protocol for identifying a surrogate decision maker as well as guidance for physicians who may run into conflict either assisting the surrogate in coming to a decision or with the decision itself. Finally, the Report offers guidelines for nurturing an effective physician-proxy relationship.

Defining Key Terms

An advance directive is a document that enables competent persons to exercise their rights to direct medical treatments in the event that they lose their decision-making capacity. Previously, the Council on Ethical and Judicial Affairs considered two general categories of advance directives: 1) a living will, which indicates the types of treatment an individual wishes to receive or forgo under specified circumstances, and 2) a durable power of attorney for health care (or a health care proxy appointment), which designates another person to make health care decisions on behalf of the patient.^{1,2}

Confusion and debate over advance directives grouped in the second category arises primarily from inconsistencies in identifying different types of decision makers, and determining the scope of their authority.^{**} This may result from the fact that although all fifty states have established

laws that govern advance directives, either statutorily or through case law, each differs in its standards and terminology.² There are also a number of different advance directives currently available, offering varying degrees of empowerment to the decision maker. Some advance directive forms combine a proxy designation with specific instructions for the proxy so that the distinctions between a living will and a durable power of attorney for health care are beginning to blur. For the purposes of this report, the term “proxy” will be used to refer to a person who has been chosen by the patient, through a documented advance directive, to be the substitute health care decision maker, while the term “surrogate” will refer to a person whose authority to make health care decisions for a patient is based on state statute, case law, or a decision made by the medical team such as a physician or ethics committee.

Making Decisions For Incompetent Patients

There are two basic principles that should guide any treatment decisions: respecting and promoting patient autonomy, and fostering the well-being of the patient.¹ The same right of self-determination that underpins the doctrine of informed consent provides legitimacy for the use of advance directives; that is, the patient’s right to choose a course of action remains after he or she loses decision-making capacity. Likewise, provisions should be made to respect the patient’s wishes even after competence is lost.³

To protect the well-being and autonomy of the incompetent patient, three standards have been established in ethics and law to such guide decisions. These standards are referred to as: 1) the documented advance directive, 2) substituted judgment, and 3) the best interest standard.

Documented Advance Directives

The designation of a proxy through a durable power of attorney for health care and the implementation of a living will are often effective ways to ensure the appropriate implementation of the patient’s preferences with regard to health care decisions.¹ While a detailed living will may ensure that decisions will accurately reflect the patient’s wishes in anticipated situations, a pre-designated proxy may be more suitable to interpret the patient’s wishes in unforeseen circumstances. To have the benefits of both a living will and a durable power of attorney, patients may document a proxy designation and, while competent, discuss with their proxy the preferences, values, or specific instructions that should be considered when making treatment decisions. Traditionally, advance directives have been associated with end-of-life decisions. However, health care directives that can be used in any circumstance in which a patient is incompetent or incapacitated are more effective and desirable.

Substituted Judgment

When a patient does not have documented treatment preferences or goals, decisions concerning the incompetent patient’s health care should proceed by substituted judgment. Substituted judgment asks that someone who knows the patient attempt to make a decision in the manner that the patient would (if he or she were capable of making the decision).^{1,3} The decision maker should look to the patient’s previously expressed preferences and values to determine what the patient would have decided. Substituted judgment is a valuable guiding principle because it gives weight to the subjective nature of medical decisions.

However, much empirical research indicates a low correlation between proxies’ decisions and what patients would have decided in hypothetical situations.^{4,5} Because there is no direct deductive relationship between values and a particular choice, or between previous decisions and current

positions, the surrogate is often left to make an approximation of what the patient would have wanted.⁴ At best, substitute decision making requires great imaginative effort to process a patient's web of values, preferences, and medical judgments.^{2,4}

With the recent criticisms of the substituted judgment standard, some authors have offered an alternative that is similar and in some ways more amenable to thinking about a medical decision. Rather than attempt to predict what the patient would say about treatment preferences, the patient's life story is considered, and a particular option is evaluated in terms of its "fit" with the elements of the patient's life story.³ This narrative model rests on the idea that individuals create an identity for themselves through their life story and it is through this narrative that persons conceptualize themselves. Thus, the physician and the surrogate have a *prima facie* moral obligation to continue the story in a manner that is meaningful and consistent with the patient's self-conception. It is possible that more than one choice is compatible with the patient's self-conception. Thus, the narrative approach seems to avoid the problems that arise from trying to predict which single course of action the patient would have decided when competent, as well as problems that arise when making decisions for patients who may have never been completely competent.⁶

Best Interest Standard

Traditionally, when there has been no reasonable basis for interpreting how the patient would have decided, surrogate decision makers have based treatment decisions on predicted outcomes that would most likely promote the patient's well-being.¹ This guiding principle is referred to as the "best interest" standard and is most often invoked for patients who have never possessed decision-making capacity or for those whom an appropriate surrogate cannot be identified. Making a decision based on another's best interests is less an act of respecting the patient's autonomy than it is an expression of beneficence. Employing this standard requires a more objective analysis of the harms and benefits of various options. Factors that should be considered when weighing the harms and benefits of various options include the pain and suffering associated with treatment, the degree and potential for benefit, and any impairments that may result from treatment.^{1,7}

While some courts and scholars have used the term "objective standard" to characterize best interest reasoning, the subjective perspective of the surrogate decision maker will unavoidably enter into judgments concerning the patient's quality of life. In the more difficult cases, the best interest standard for decision making is essentially a judgment about quality of life.⁷ For the surrogate to make an impartial decision using the best interest standard, he or she should measure quality of life as the worth to the individual whose course of treatment is in question, and not as the social worth of that life.⁸ One way to test whether a decision is inappropriately influenced by the surrogate's own values is to ask if the decision is one that most reasonable persons would choose for themselves in similar circumstances.¹

Who Should Decide

When a medical decision needs to be made for an incompetent patient, physicians should first inquire whether the patient had directly expressed wishes in a written document, such as a living will or a durable power of attorney for health care. If the patient has not left such a document, a surrogate should be appointed. Many states have codified protocols for identifying surrogates in the absence of any prior designation. In general, these statutes indicate that the family of the patient should be responsible for medical decisions. "Family" is generally understood to be the person's closest biological or legally recognized relations.¹ Many states have established a hierarchy for identifying a surrogate decision maker in the absence of a documented advance directive. The order of priority for appointing a surrogate is often listed as legal guardian of the patient first, then a

spouse, adult children of the patient, a parent of the patient, an adult sibling, and finally a close friend of the patient.

In this report, family includes whoever is closely associated with the patient. For instance, unmarried living partners and close friends should be considered as appropriate decision makers in addition to spouses, children, parents, or siblings. Recognizing this extended concept of “family” is increasingly important as alternatives to marriage and the nuclear family unit become more common.¹ In the case where there is no person who is closely associated with the patient, but there are persons who both care about and have some relevant knowledge of the patient, these persons should participate in the decision-making process, and in some situations, may be appropriate surrogates.

The family’s default authority to make medical decisions for an incompetent patient rests on a number of bases. It is often claimed that families have an intimate knowledge of the patient’s values and can best make the same medical care decisions that the patient would have made. In addition, because an individual’s values are developed primarily in the family, family members are most familiar with the patient’s entire life context. Moreover, family members are generally the most concerned with the patient’s welfare for it is the family who has traditionally provided for the patient’s comfort, care, and best interests. Finally, participation “in an intimate association is one important way in which individuals find or construct meaning in their lives.”¹

While it is common to assume that family members are best suited to determine what the patient would have decided, there is significant evidence indicating a lack of concordance between patients’ treatment preferences and family members’ prediction of those preferences.⁹ Such information has caused many to question the moral authority of the family to make decisions. However, most of these studies offer no alternative “default surrogate” that fares any better at predicting patient choices.¹⁰ Furthermore, the moral importance of the family as a social unit in which values and preferences are fostered and realized is consistently promoted and, in this case, codified into most regulations that designate a procedure for designating surrogacy.

Resolving Conflicts

Decisions which profoundly affect a loved one who is incompetent to make medical decisions can be difficult for a family due to the emotional distress resulting from the situation. It is essential for physicians and other health care providers to be sensitive to the range of emotional and psychological responses of the family. Emotionality should not be interpreted as irrationality and used to justify overriding the family’s decision-making authority. Rather, if a physician feels that the decision-making capacity of the family as a surrogate is significantly diminished by emotional distress, efforts should be made to help the family in its decisions. Offering counseling services or the assistance of an ethics committee or chaplain are examples of such efforts.

Not only is effective communication between the physician and the surrogate essential for appropriate decision making, but it also goes far in preventing major disputes among family members and health care providers. Physicians should offer relevant medical information and explanations as well as medical opinions based on professional expertise. In the absence of a documented advance directive, physicians should explain to the surrogate that decisions should be based on substituted judgment when possible, and otherwise on the best interest principle.¹

Disputes Among Family Members

Surrogates often make decisions as members of a family unit whose relationship will continue after a particular decision is made. These relationships deserve the respect of the health care team, and physicians should seek to maintain family harmony. Accordingly, physicians should not intentionally pit the interests of a particular family member against those of other family members to advocate for what the physician believes to be the most appropriate course of treatment.

In some instances, it may be appropriate to have recourse to an ethics committee. However, physicians and ethics committees should generally refrain from making treatment decisions.¹ Rather they should attempt to mediate disputes. Family members may disagree when they do not understand the medical circumstances, each other's view points, or that decisions should be made using a substituted judgment standard whenever possible. Physicians and ethics committees should try to facilitate an understanding of these factors.

Sometimes, a single designated surrogate can resolve a case in which several family members disagree.¹¹ However, differences may arise when the patient has not designated a proxy and the family cannot agree on which member should act as the surrogate. Physicians or ethics committees should explain that the people who have the best understanding of the patient's values will likely make a decision that reflects what the patient would have decided. Specifically, this refers to people who have had fairly involved and recent discussions with the patient about life, death, illness, religion, and/or specific treatments. Therefore, factors that may guide the search for an appropriate surrogate include the amount of personal contact with the patient, amount of recent personal contact, and the amount of dedication to the patient.¹

Disputes Between Physicians and Surrogates

Physicians should generally respect decisions based on well-reasoned substituted judgment or the best interest standard, even if the decision results in a different course of treatment than the physician recommended. Religious and culturally based decisions that reflect beliefs or values held by the patient also should be respected. However, no choice, no matter how well intentioned, should make physicians agents of harm. Such conflicts pit the professional integrity of the physician and well-being of the patient against the ethical obligations to respect the patient's delegated autonomy.¹¹

When a physician challenges the decision of a surrogate, an ethics committee should first verify that the challenge is based on a belief that the decision is clearly not what the patient would have decided or, cannot reasonably be judged to promote the patient's well-being.¹ In most cases, a negotiated understanding of the patient's values or best interests offers the best protection for the relationship between physicians and surrogates.¹¹

In the event that a conflict is intractable, even after consulting an ethics committee, the dispute should be referred to the courts.¹ A tremendous disservice is done to the family and the patient when the decision-making process is unnecessarily brought into a forum that is burdensome and adversarial. Traditionally, ethics committees are more informal than the courts, and can maintain the privacy of the family decision-making process better than judicial review, putting less strain on the family and its relationship with the physician or hospital. It is strongly encouraged that when judicial review becomes necessary, the courts appoint an appropriate surrogate to make decisions rather than making treatment decisions.¹

The Proxy-Physician Relationship

With the rise in the use and discussion of advance directives and surrogate decision makers, the doctor-proxy relationship has fallen under increased scrutiny. Research has shown that proxies and surrogates frequently feel marginalized in the decision-making process.² This may be a result of misunderstandings regarding the role and authority of health care proxies and surrogates, or that physicians tend to predetermine the “correct” medical decision and promote that option before the decision maker.² While some physicians feel that a medical decision should be discussed only among the family members or decision makers, proxies and surrogates are usually eager to receive information about the patient’s condition and appreciate guidance helping them to make decisions that reflect the patient’s wishes or best interests.²

Recognizing the proxy or surrogate as an extension of the patient, entitled to the same respect and professional obligations as the decisionally capable patient, and eliciting his or her active participation in discussions and decisions can only enhance the quality of care provided to the patient. These obligations include, but are not limited to, providing the decision maker with timely and accurate information about the patient’s diagnosis, prognosis, and treatment options; confidentiality of the discussion between physician and proxy or surrogate; and an acknowledgement that he or she is entitled to receive advice, guidance and support.² Surrogates are frequently asked about further treatment at the same time they are given the news about their loved one becoming incompetent. If possible, surrogates should be given time to absorb this new information before being asked about further treatment.¹¹

When disputes or conflicts arise, physicians should use this time to address the barriers to agreement. For instance, a physician could hold a family meeting to elicit and respond to the concerns of the entire family. Mediation and negotiation techniques are important to resolving any sort of dispute. If a physician simply facilitates discussion to help parties clarify issues and come to a mutually satisfactory solution, he or she becomes less of an arbiter and may avoid appearing confrontational. This allows physicians to support a family’s final decision and to share the burden of more difficult decisions with the decision maker or surrogate. The uncertainty that accompanies many medical decisions is compounded by knowing that the consequences of the decision will affect a vulnerable and dependent loved one. Thus, support for decision makers should be offered so that they do not feel alone in their decisions. Such support may include counseling services, access to an ethics committee, social services, or spiritual support.

Although patients cannot always anticipate their future medical conditions or health care needs, they can begin the process of advance care planning. Physicians should urge each of their patients to appoint a health care proxy and to discuss with that person health care wishes and goals.^{12,13} Physicians should also present other options such as a living will.¹⁴ During these discussions it is important for physicians to remain sensitive to and respect religious and cultural issues that may be central to the patient’s identity. If physicians take the time to encourage advance care planning with competent patients, they may avoid the difficulties associated with seeking out and appointing an appropriate surrogate.

Conclusion

To ensure that the autonomy of an individual patient is maintained in the case of injury or illness that results in incompetence, physicians should respect any advance directive that a patient holds. To further secure the autonomy of an incompetent patient in the absence of an advance directive, a surrogate decision maker should be identified. In this case, the decision maker should adhere to a

substituted judgment standard when there is evidence of what the patient would have decided or, in the absence of such evidence, select the course of treatment that most likely promotes the patient's well-being. Physicians should discuss with patients various options related to advance directives and the benefits of having directives in place before the need for such decisions arise.

Recommendations

The Council recommends that the following be adopted and the remainder of the report be filed:

Competent adults may formulate, in advance, preferences regarding a course of treatment in the event that injury or illness causes severe impairment or loss of decision-making capacity. These preferences should be followed by the health care team out of respect for patient autonomy. Patients may establish an advance directive by documenting their treatment preferences and goals or by designating a proxy to make health care decisions on their behalf.

If an incompetent patient is to receive medical treatment, a reasonable effort should be made to identify the presence of an advance directive. When such a patient lacks a documented advance directive, or when reasonable efforts have failed to uncover such documentation, physicians should defer to state law to identify a surrogate decision maker. In the absence of state law, the patient's family, or persons with whom the patient is closely associated such as close friends or domestic partners, should become the surrogate decision maker. In the case when there is no family, but there are persons who have some relevant knowledge of the patient, such persons should participate in the decision-making process. In all other instances, a physician may wish to utilize an ethics committee to aid in identifying a surrogate decision maker or to facilitate sound decision making.

When there is evidence of the patient's preferences and values, decisions concerning the patient's care should be made by substituted judgment. This entails considering the patient's advance directive (if any), the patient's values about life and how it should be lived, how the patient constructed his or her identity or life story, and the patient's attitudes towards sickness, suffering, and certain medical procedures.

In some instances, a patient with diminished or impaired decision-making capacity can participate in various aspects of health care decision making. The attending physician should promote the autonomy of such individuals by involving them to a degree commensurate with their capabilities.

If there is no reasonable basis on which to interpret how a patient would have decided, the decision should be based on the best interests of the patient, or the outcome that would best promote the patient's well-being. Factors that should be considered when weighing the harms and benefits of various treatment options include the pain and suffering associated with treatment, the degree of and potential for benefit, and any impairments that may result from treatment. Any quality of life considerations should be measured as the worth to the individual whose course of treatment is in question, and not as a measure of social worth. One way to ensure that a decision using the best interest standard is not inappropriately influenced by the surrogate's own values is to determine the course of treatment that most reasonable persons would choose for themselves in similar circumstances.

Physicians should recognize the proxy or surrogate as an extension of the patient, entitled to the same respect as the competent patient. Physicians should provide advice, guidance, and support; explain that decisions should be based on substituted judgment when possible and otherwise on the best interest principle; and offer relevant medical information as well as medical opinions in a timely manner. In addition to the physician, other hospital staff or ethics committees are often helpful to providing support for the decision makers.

In general, physicians should respect decisions made by the appropriately designated surrogate on the basis of sound substituted judgment reasoning or the best interest standard. In cases where there is a dispute among family members, physicians should work to resolve the conflict through mediation. Physicians or an ethics committee should try to uncover the reasons that underlie the disagreement and present information that will facilitate decision making. When a physician believes that a decision is clearly not what the patient would have decided or could not be reasonably judged to be within the patient's best interests, the dispute should be referred to an ethics committee before resorting to the courts.

Physicians should encourage their patients to document their treatment preferences or to appoint a health care proxy with whom they can discuss their values regarding health care and treatment. Because documented advance directives are often not available in emergency situations, physicians should emphasize to patients the importance of discussing treatment preferences with individuals who are likely to act as their surrogates.

REFERENCES

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- ² Post LF, Blustein J, Dubler NN. "The Doctor-Proxy Relationship: An Untapped Resource." *Jrnl. of Law Medicine & Ethics*. Spring 1999; 27(1): 5-12.
- ** In the interest of clarity and accuracy, the terms *proxy* and *surrogate* are distinguished in the following manner: a *legally appointed proxy* refers to a person who has been chosen and legally appointed by a patient to be the substitute health care decision maker; a *surrogate by state law* refers to a person whose authority to make health care decisions for someone else is based on state statute or case law; and an *informal surrogate* refers to a person who is asked by the medical team to help make treatment decisions because no one has been appointed by the patient or is legally authorized.
- ³ Kuczewski, MG. "Narrative Views of Personal Identity and Substituted Judgement in Surrogate Decision Making." *Jrnl. of Law Medicine & Ethics*. Spring 1999; 27(1): 32-36.
- ⁴ Emanuel EJ and Emanuel LL. "Proxy Decision Making for Incompetent Patients." *JAMA* 1992; 267(15): 2067-2071.
- ⁵ Suhl J, Simons P, Reedy T, Garrick T. "Myth of Substituted Judgement: Surrogate Decision Making Regarding Life Support is Unreliable." *Arch Intern Med* January 1994; 154: 90-96.
- ⁶ The narrative approach shifts the focus of the decision from what the patient would have decided, which is an aspect of substituted decision making that has been the focus of several studies, to deciding on an option that best fits with the patient's life-story or self-identity. This is also helpful in cases where patients have never been competent. Traditionally, a guardian of a patient that has never been competent would invoke the best interest standard to make a medical decision because it is not possible to infer what this patient would have decided. However, some would argue that it is possible to develop a relationship with an incompetent or incapacitated individual where the individual's goals and values can be clearly understood even though they have never been clearly articulated or expressed. Thus, the narrative approach to substituted decision making is more amenable to making decisions for patients that have never been competent to make a medical decision
- ⁷ Drane JF and Coulehan JL. "The Best Interest Standard: Surrogate Decision Making and Quality of Life." *Journal of Clinical Ethics* Spring 1995: 20-29.
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