

Surrogate Decision Making in Neurocritical Care

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ABSTRACT

Patients with critical neurologic illness typically have impaired capacity to make their own medical decisions. In these cases, neurologists need to make medical decisions based on advance directives (such as a living will) or the decisions of a surrogate. A hypothetical case of a 60-year-old man with an intracerebral hemorrhage is used to highlight some of the difficulties that can occur when attempting to apply general statements made in a living will to a specific medical treatment decision. The ethical and legal issues surrounding surrogate decision making as they apply to acute critical neurologic disease are discussed, along with suggestions for how to resolve potential disagreements.

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Case

Note: This is a hypothetical case.

A 60-year-old man with hypertension developed acute left hemiparesis. He was found to have a moderate-sized right hemisphere intracerebral hemorrhage with intraventricular extension and hydrocephalus. Shortly after arrival to the emergency department, his level of consciousness declined and he was intubated for airway protection.

In talking with the medical team, his wife and grown children noted that he had frequently said that he “did not want to end up like a vegetable.” He had a living will that stated, “If I become terminally ill or permanently unconscious my desires for treatment include no aggressive measures to extend my life.” His wife had paperwork that indicated she had durable power of attorney (DPOA) for health care decisions.

The medical team wanted to place a ventriculostomy because they suspected his decreased level of consciousness was related to elevated intracranial pressure. His wife and his grown son felt that he would not want to live in his current state and were considering avoiding surgery and initiating comfort measures. His grown daughter thought proceeding with comfort measures was premature because her father was “always a fighter” and would want to “have a chance.”

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This case raises the following ethical questions:

- How should physicians work with family members to resolve disagreements about treatment for patients with impaired capacity in order to make medical decisions?
- What are the strengths and weaknesses of advance directives?
- Are there limits to the types of decisions that a surrogate can make for a patient who lacks decisional capacity, and do these limits differ depending on whether the surrogate has DPOA for health care decisions?

DISCUSSION

When patients cannot make their own treatment decisions, a mechanism must be in place to make decisions on their behalf. Decisions are typically enacted by a surrogate decision maker either with or without the use of a written advance directive, such as a living will. Surrogate decision making is common in neurocritical care, as patients often have impaired decision-making capacity due to their underlying brain injury.

This case demonstrates several potential disagreements that can occur during the process of surrogate decision making. The first disagreement occurs within the patient's family over the interpretation of the patient's living will and his prior statements about what he might want in this situation. The second disagreement occurs between the treating team, who feel that a ventriculostomy is indicated on an urgent basis, and the patient's wife, who does not want to permit insertion of a ventriculostomy based on her understanding of her husband's advance directive. Resolving these disagreements can be aided by a review of the principles that underlie surrogate decision making.

There is an established hierarchy of standards by which decisions can be made on behalf of an individual with impaired decision-making capacity.¹ The highest priority should be given to enacting the patient's previously expressed wishes. Written documents are generally given more weight than verbal statements, unless the verbal statement is in the form of an oral advance directive witnessed and documented by a physician. If the patient's wishes are unknown, the next highest standard is based on the principle of substituted judgment, in which a surrogate decision maker (typically a family member) makes the decision that he or she feels the patient would have made, based on an understanding of the patient's values and preferences. Finally, if no information about the patient's values and preferences is available, decisions should be made according to the best interest standard. The best interest standard involves looking at risks and benefits of a treatment and making decisions according to how a reasonable person would be expected to balance those risks and benefits.¹

This patient has a written living will that should be the first place to turn for guidance when deciding on the appropriate treatment. However, many problems with living wills have been reported.² Statements in these documents are often vague and can be open to interpretation when applied to a specific medical decision.³ Additionally, treatment preferences stated when healthy can evolve when a person is facing serious illness.⁴ Finally, living wills typically apply only in the setting of terminal illness, permanent unconsciousness, or other end-stage conditions. A living will may not take effect in the common scenario of a patient facing serious illness with a high probability of death or disability but some

possibility of a good recovery, such as the case described here. Despite these limitations, the treating team is obligated to review the living will and assess its relevance to the current clinical situation because it will provide insight into the patient's previously expressed preferences.

Because of the above limitations, written advance directives are not sufficient to inform medical decision making in isolation and must be interpreted by a surrogate and the health care team. The appointment of a surrogate decision maker, or health care proxy, with DPOA for health care decisions has many advantages over a written advance directive. The authority to make health care decisions with DPOA is not limited to cases of terminal illness and applies in any setting where decisional capacity is impaired. Furthermore, use of a health care proxy familiar with the patient's values and wishes allows for the flexibility to deal with the complex and rapidly changing situations that are common in critical illness. If the patient has not specifically designated a proxy for health care decisions in advance, most states provide guidance regarding the hierarchy of who may serve as a surrogate decision maker—typically a spouse, followed by grown children, and then additional family members.⁵ However, there may be limits placed on the types of decisions that can be made by surrogates appointed through this default mechanism, although these limits vary depending on state law.⁵ Because state laws can differ substantially, readers are advised to be familiar with the laws in the states or jurisdictions where they practice.

While the use of a legally authorized surrogate decision maker is widely recommended, surrogate decision making based on substituted judgment is not without problems. Studies have shown that surrogates are not always able to accurately predict patients' preferences.⁶ Additionally, serving as a surrogate decision maker can be a substantial emotional burden for a family member.⁷ Despite these limitations, a surrogate making a decision using substituted judgment is still preferable to making a decision based on the best interest standard as it may better preserve patient autonomy.¹

It is a tempting and common practice to focus initial discussions with family members on specific treatments or procedures. However, the preferred approach is to discuss overall goals of care first.^{8,9} The goals of care should be based on the patient's previously expressed values and preferences and can then guide other more specific treatment decisions. Common goals of care include prioritizing comfort over length of life, survival at any cost regardless of disability, or survival only if disability is minimized. Once the goals of care have been established, the treating team can help the family understand the patient's current condition and whether the various treatment options will be able to achieve the goals of care.

If families seem unable to reach a consensus or are struggling with the emotional burden of the decision process, a specific treatment recommendation can be provided.⁹ However, since not all surrogates want to receive a treatment recommendation, they should first be asked if they would like to hear a recommendation.¹⁰ Offering a recommendation may be particularly helpful in this case because the family cannot reach a consensus and a decision about ventriculostomy must be made urgently. The treating team may also wish to highlight the uncertainty regarding prognosis after intracerebral hemorrhage^{11,12} and can stress that his condition and goals of care can be reassessed in 24 to 48 hours.

What if the patient's wife were to continue to insist on no ventriculostomy despite some concern raised by his daughter that this may not be consistent with the patient's wishes? His wife has DPOA for health care decisions; therefore, she has the sole legal authority to make any decision that the patient could make, including refusal of treatment such as a ventriculostomy even when his prognosis is not necessarily terminal. His daughter's rather general statement that "he was always a fighter" is not sufficient to overrule the legal authority of the patient's wife to refuse treatment. However, effort should be made to reach an agreement on the treatment plan among family members when possible. His daughter's statement should be explored more fully with the family to determine if the patient ever made specific statements about treatment preferences if he were facing serious, but not necessarily terminal, illness. If a consensus cannot be reached, consultation with the hospital ethics committee may help to resolve the conflict, although ultimately the legal authority to make decisions still lies with the patient's wife.

Discussions with surrogate decision makers about the treatment of loved ones are emotionally charged conversations that occur frequently in neurocritical care. Navigating these interactions is an important skill for any neurologist who practices in a critical care environment. With careful attention to the legal and ethical principles that underlie surrogate decision making, physicians and families can work together to make the best decisions for patients with critical neurologic illness.

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