

Palliative Care Rounds: Toward Evidence-Based Practice

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Responding to Surrogate Requests That Seem Inconsistent With a Patient's Living Will

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Abstract

Clinicians may feel conflicted when a patient's legal decision maker is making decisions that seem inconsistent with a patient's living will. We provide evidence-based information to help clinicians consider whether a surrogate's inconsistent decisions are ethically appropriate. Surrogates are not flawless translators of their loved one's preferences; they are influenced by their own hopes and the current clinical context. Patients may be aware of this, are often concerned about burdening their loved ones, and often grant their surrogates leeway in interpreting their wishes. When appropriate, clinicians should respect surrogates' interpretations of patient values and take steps to decrease surrogate stress during the decision-making process. Finally, if clinicians are cognizant of their own values and preferences, they may recognize how these may affect their responses to certain clinical cases. J Pain Symptom Manage 2011;42:777–782. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Surrogates, decision making, advance directives, substituted judgment

Introduction

The Case

Mrs. J is an 82-year-old widowed woman with a history of mild congestive heart failure, chronic kidney disease, and diabetes. She has

been living independently, although she has reported increased fatigue. One day she meets friends at the mall and collapses. She is intubated in the field and admitted to the intensive care unit (ICU) of the local hospital. Her only child, Richard, is identified as her legal decision maker. After meeting with the medical team, he reports that his mother enjoys life and is not ready to give up. He asks that efforts be continued to keep her alive as she recovers from urosepsis and a non-ST elevation myocardial infarction. During the next two weeks,

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attempts to manage her worsening heart failure result in acute kidney injury. She suffers a gastrointestinal bleed. She remains intubated and sedated. Her medical team is concerned that she soon may need dialysis, a tracheostomy, and a permanent feeding tube. Richard visits her daily. During her third week in the ICU, Mrs. J's sister arrives from out of town with a copy of a living will Mrs. J prepared eight years previously, which outlines that she would not want to be intubated, receive feeding by a tube, or receive dialysis if her condition was "terminal." Her sister explains that Mrs. J prepared this document after her experience with their brother, who spent six weeks in an ICU before his death from metastatic lung cancer. The document does not name a power of attorney for health care. Her medical team discusses her living will with Richard, who reports that his mother completed the living will when she was extremely healthy and could not imagine living with any disability. He asserts that she is not "terminally ill" and would want aggressive care continued if she could be asked today because she would want the chance to get better. The medical team believes that her chances of surviving the hospitalization are low but are unsure whether she should be considered "terminally ill." Although the team recognizes that Richard is her legal decision maker, they are concerned that continuing life-sustaining treatments may go against Mrs. J's previously stated preferences and are not sure how to proceed.

The Clinical Questions

Mrs. J's medical team would like the surrogate decision maker to use substituted judgment or the act of making decisions that most people would agree the patient would have chosen for herself. The team is unsure how to respond when the surrogate does not appear to be making decisions that are consistent with the patient's preferences outlined in her living will. In trying to decide about whether the son's actions are ethically appropriate, Mrs. J's medical team wonders about two questions:

1. How accurately do surrogates represent patient preferences?
2. What should be done when a surrogate decision maker's interpretation of the

patient's care preferences differs from the clinicians' interpretation?

Searching the medical literature can provide guidance to these clinical questions. The medical team's first question can be answered through a basic search of the literature. The second question, however, is too broad and must be broken down into more focused questions before it can be answered:

- 2a. How stable are patient preferences? If they change, are the changes predictable?
- 2b. What do patients think should be done when the living will and surrogate decisions differ? Why?
- 2c. Is it ethical to consider not only the patient's preferences, but also the surrogate decision maker's needs during decision making?

Addressing the Questions

Each member of the writing team took one question and searched the literature for pertinent articles. We identified additional articles by examining references from the original articles, searching medical databases, and consulting with medical librarians. Because aspects of these questions have been addressed by numerous articles, we did not attempt a comprehensive literature review but instead tried to identify one or two high-quality studies that answered the questions as closely as possible.

How Accurately Do Surrogates Represent Patient Preferences?

Several studies have examined the concordance between patients' stated preferences for care in future, hypothetical medical scenarios, and estimates of patients' preferences by their designated decision makers. In 2006, Shalowitz et al.¹ performed a systematic review of patient-surrogate concordance studies and concluded that surrogates accurately predicted patients' preferences approximately 68% of the time. Unfortunately, they did not find evidence that previous discussions about care preferences improved accuracy. Although not perfectly concordant, surrogates proved to be more accurate than others, such as physicians. Additional studies have noted that surrogates'

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