

Jason H.T. Karlawish, MD; Timothy Quill, MD; and Diane E. Meier, MD, for the ACP–ASIM End-of-Life Care Consensus Panel

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Making palliative care decisions for a patient who lacks decision-making capacity presents several challenges. Other people, such as family and caregivers, must choose for the patient. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision. This paper presents a case study of a patient with severe Alzheimer disease who has two common clinical problems: neurogenic dysphagia and aspiration pneumonia. The case study describes a consensus-based decision-making strategy that keeps what is known about the patient's wishes and values in the foreground but also expects guidance from the physician and elicits input from family members and other people who care for and have knowledge about the patient. The steps of this process, including key clinical prompts and potential transition statements, are outlined and described. The overall goal of the case commentary is to demonstrate that physicians can guide a highly emotional and personal process in a structured manner that has meaning for the patient, family, physician, and other caregivers.

heimer's over 7 years ago, but I have only known her for the last few months. Can you tell me how she seems to you now, and how things have changed compared to when she was first admitted?"

The family's story begins with a summer vacation cut short when Mrs. B. fell and was hospitalized for 10 days. She never fully recovered and subsequently experienced a progressive loss of function over the next 7 years. The physician responds to the story by saying, "I think I have a better understanding about how things have changed over the past few years. It sounds like both you and she have done the best you could through a difficult situation. You know that Mrs. B. has an incurable, progressive, and ultimately fatal disease. I can't say for sure when she'll die of her Alzheimer's disease, but given its severity, we shouldn't be surprised when she does. Even if she does recover from this pneumonia, she will not recover her swallowing function. Recognizing this, we ought to care for her in a way that makes us confident that after she's gone, we can say she was treated with dignity and respect.

"I use two principles to help think through the decisions we face. First, consider your understanding of what Mrs. B. would want if she could tell us. Second, we should balance the burdens and benefits of each option in terms of its ability to relieve her suffering and maximize her dignity and the quality of her remaining life."

This narrative begins an emotional and meaningful dialogue that should lead to a consensus about the best way to care for Mrs. B. given her clinical circumstances. This consensus-based approach is distinct from a discussion in which individuals simply share their opinions, but there is no genuine

sharing of narratives may expose important differences in beliefs and understandings in any of these domains that must be reconciled before consensus-based decision making can proceed. The more the physician understands these various perceptions, the more likely he or she is to develop a plan that will respect Mrs. B. as a person. Even when the physician has a long-term relationship with the family and patient, this step in consensus building should not be skipped. Research showing that physicians often inadequately understand their patients' preferences for health care supports this point (9–11).

The next step in consensus building is to begin a dialogue about prognosis and about the potential role of palliative care. This was done with the phrase that began “Unfortunately, Mrs. B. has an incurable, progressive, and ultimately fatal disease. . . .” Although this physician believes strongly in a palliative approach that includes pain and symptom management and avoidance of invasive treatments for patients with severe Alzheimer disease, he must respect that others may value an approach in which available medical technology must always be used to prolong life. Before a consensus about what might be included in a palliative approach for a particular patient is possible, the physician must learn what “treated with dignity and respect” means in this family.

Finally, the physician guided the family on ethical standards for decision making: 1) Consider what is known of the patient's wishes and preferences given her current condition (for example, a living will or potentially relevant statements made when the patient was competent) and 2) balance the burdens and benefits of each option in terms of its ability to maximize Mrs. B.'s dignity and quality of life. Deciding how to care for Mrs. B. by using only a rigid understanding of her past preferences may fail to respect her present circumstances (12). Achieving

case, the daughter and the physician thought that Mrs. B. had a poor quality of life and were concerned that hospitalization and even antibiotics might further decrease her quality of life. The husband disagreed. They all were genuinely trying to act in Mrs. B.'s best interests without clear information about her preferences. They achieved compromise with the decision to give Mrs. B. a therapeutic trial of antibiotics at the nursing home.

Dialogue is essential for achieving consensus on a course of action that is responsive to both past and present patient realities, as well as to the concerns and priorities of the family (5, 6, 16). The goal of dialogue is not to provoke conflict but to clarify common ground and differences and lead to better appreciation of the meaning of the decision for the patient and her family (5, 17). This approach to decision making is grounded in narrative theory that unifies the clinical and moral dimensions of medicine (18, 19). Clinical medicine is grounded in a series of stories told and interpreted from a variety of perspectives. The physician usually interprets these stories, using the science of clinical medicine, to develop a diagnostic and therapeutic plan. These same stories can be simultaneously used to understand the patient's values, goals, and meanings of illness, which should guide the personal and moral sides of the same process. Narrative theory was put into practice when the physician prompted Mr. B. and his daughter to describe their perception of Mrs. B.'s current condition, as well as how she has changed over recent years. The physician also shared his own perceptions. Reconciling the perceptions conveyed in these stories decisively shaped the process of medical decision making on Mrs. B.'s behalf.

This theory has some limitations. Consensus occurs in the context of choices. However, in the care of patients with severe dementia who live in nursing homes, local customs, beliefs, and systems of care can limit reasonable choices. For example, long-term care regulations are often wrongly believed to require that all residents with neurogenic dysphagia receive artificial nutrition and hydration. Surrogate decision-making laws are often misinterpreted to require a legally designated guardian for noncompetent patients who lack an advance directive (3). Although a few state laws (in Missouri and New York) require a high degree of proof of a surrogate decision maker's knowledge of a patient's wishes to allow the surrogate to withhold or withdraw artificial hydration or nutrition from noncompetent patients, most states support the legal right of surrogate decision makers to refuse any and all unwanted medical treatments when this decision is based on a consensus of the patient's wishes and best interests (3). In addition to legal inconsistencies and misper-

*pleasure Mrs. B. received from her husband's daily visits and the food that he gave her.*

*The husband becomes agitated. "I just can't starve her, watch her starve, if that's what you're saying." He begins to weep.*

*"But Dad, she eats what she wants. No one's saying don't feed her. It's just don't force-feed her."*

*"But how will we know she's hungry?" he asks.*

*The physician offers a suggestion. "Her eating and your feeding her is one of the few meaningful activities that she has left. I think you both agree that we ought to at least allow her to try some food by mouth.*

port as medical choices that ultimately shape the