

Virtual Mentor

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ETHICS CASE

Questions about an Advance Directive

Commentary by Bernard J. Hammes, PhD, Thomas D. Harter, PhD, Meera Balasubramaniam, MD, MPH, and Yesne Alici, MD

Mrs. Erickson lives in a long-term care facility. At 72, she has hypertension, mid-stage Alzheimer disease, and aortic stenosis complicated by congestive heart failure. It has become challenging to manage her fluid balance on an outpatient basis. When she was admitted to the inpatient teaching service from the dementia unit of her care facility with acute decompensation due to heart failure, an echocardiogram indicated that her aortic stenosis had progressed to a severe stenosis stage, and she was admitted to the hospital. Mrs. Erickson is able to interact with caregivers intermittently and is able to participate in her activities of daily living (ADLs), although she requires assistance with all of them.

Mrs. Erickson has a 15-year-old advance directive in which she indicated that, should she not be able to make decisions about her care, she wanted the benefit of all available medical interventions to preserve her life. At the time the advance directive was prepared, Mrs. Erickson had mild hypertension that was fairly well controlled with dietary changes, and no signs of Alzheimer disease. She was living alone and working full-time and named her only daughter as the person with durable power of attorney for health care.

Shortly after Mrs. Erickson entered the care facility seven years ago, her daughter died, so that now her 19-year-old granddaughter, Caitlin, is her next of kin. Caitlin was not mentioned in Mrs. Erickson's advance directive, and she says that she and her grandmother have never discussed end-of-life care.

After a thorough presentation of Mrs. Erickson's history and status by the intern of the team, the attending physician suggested offering her an aortic valve replacement as a therapeutic option. This sparked lengthy discussion among the team members, who finally decide to discuss the options with Caitlin. The resident on the team, Dr. Marx, felt ill at ease about the prospect of surgery. Even though the patient clearly indicated that she wanted all interventions, Dr. Marx thought that, if she could make this decision in her current state of health, she would choose not to pursue this route.

Caitlin came in for the discussion of the risks and benefits of various options. After hearing what the team has to say, she sighed. "This is a really tough decision. Frankly, I'm not sure what to do. Do you think surgery is the best option?"

Dr. Marx does not know how to respond; the patient has a clear clinical need for surgery and previously indicated that she wanted everything done to preserve her life. Yet he believes she would not choose that option in her current state of health.

Commentary 1

by Bernard J. Hammes, PhD, and Thomas D. Harter, PhD

We will comment on two aspects of this case. First, we will discuss why we think this case is an example of poor advance care planning. Second, we will discuss how we would move this case forward via an ethics consultation.

It is our opinion that not all advance care planning programs are equally beneficial to patients. In our experience good advance care planning programs have at least two features: (1) they have processes and systems in place to help people thoroughly reflect on and communicate their values, preferences, and goals of treatment, including a discussion about what circumstances would change a person's goals from wanting full treatment with a curative intent to wanting comfort measures that aim only to ease the dying process; and (2) they are responsive to changes in a person's medical condition over time. When people undertake advance care planning that does not include these features, the plans they create are at risk for being ambiguous and causing confusion rather than clarity for third-party treatment decision makers.

We infer that Mrs. Erickson's advance care planning process was poor because these two features are absent from the case description. Regarding the first feature—reflection on and communication of values—it is unclear what she means by wanting “the benefit of all available medical interventions to preserve her life.” Did she mean “all medical interventions” regardless of their predicted success, or would she reject treatments that she considered overly burdensome? By “preserve her life,” did she mean being alive, being conscious, both, or something else? Regarding the second feature—responsiveness to changing health status—Mrs. Erickson's advance directive appears not to have been updated since it was first completed when she was living independently and was significantly healthier than she is now. The failure to work with Mrs. Erickson to update her advance directive at any point at which her health notably changed—such as when her hypertension progressed to congestive heart failure, when she developed Alzheimer disease, or when she could no longer independently care for herself—calls into question whether her advance directive is still an accurate reflection of her wishes.

The situation occasioned by this faulty advance directive is doubly ironic: first, a document intended to guide Mrs. Erickson's treatment has effectively hindered the decision-making process it was supposed to clarify. Since her advance directive was completed when Mrs. Erickson was still in relatively good health and living independently and was never updated, it is unclear whether she would still want full treatment in her current, declining state of health. Second, the ethics consult necessitated by this lack of clarity may result in an outcome that Mrs. Erickson might have opposed if she still had decision-making capacity.

To resolve this case via an ethics consultation, we begin with the facts. We know that Mrs. Erickson's granddaughter, Caitlin, does not know her values, wishes, or goals of care beyond what is stated in her advance directive. We also know that Mrs. Erickson's advance directive may not reflect her current values and treatment preferences. Furthermore, we know that Mrs. Erickson's current baseline functioning involves intermittent interaction with others and that she needs assistance with all her daily living activities. We also presume that Mrs. Erickson's treatment team—as the inpatient teaching service—would not be the team that performed the aortic valve replacement surgery.

Two pieces of information must be gathered at this point. First, we do not know the extent to which Mrs. Erickson is interactive and able to participate in treatment discussions. When a patient lacks treatment decision-making capacity, he or she lacks the ability to understand and reason with information pertinent to making a treatment decision [1]. Lacking this ability, though, does not mean that patients necessarily have lost the ability to have or communicate their values, goals, and treatment preferences, such as what gives them pleasure, what fears they have about their illnesses or injuries, or what outcomes they hope treatment will achieve. It might be the case that Mrs. Erickson cannot engage in any meaningful communication and that she only answers questions in gibberish. However, if Mrs. Erickson is somewhat communicative, she might be able to express basic preferences or values that can guide, or at least help contextualize, treatment decision making. For example, she might tell the treatment team that her greatest pleasures in life are daily walks outside and eating fried foods—values that appear to contradict surgery. Conversely, she might state that all she wants is to live a long life regardless of where she resides—a preference that appears to indicate surgery.

Second, we do not know the scope of the granddaughter's decision-making authority. If Caitlin were Mrs. Erickson's power of attorney for health care, she would have the authority to make treatment decisions that she believes are in Mrs. Erickson's best interests. However, in the case as described, Caitlin is neither Mrs. Erickson's power of attorney for health care nor her legal guardian. Caitlin's authority to make treatment decisions for Mrs. Erickson will therefore depend on the laws of the state where Mrs. Erickson is being treated [2]. For example, some states, like Ohio, legally recognize a hierarchy of treatment decision makers for patients without either a power of attorney for health care or a legal guardian. Other states, like Wisconsin, do not have such treatment decision-making hierarchies.

As respect for patient autonomy has become a common fixture in treatment decision-making processes, it is ethically obligatory for physicians to offer and provide treatments that accord with patients' known preferences. However, physicians in the United States also have professional, ethical, and legal responsibilities to maximize patient well-being and minimize patient suffering. Treatment decision making is thus based on a combination of patient preferences and sound medical judgment.

That the resident in Mrs. Erickson's case believes she would not want surgery is irrelevant in our assessment because it appears to be based on his subjective interpretation of Mrs. Erickson's quality of life. If the resident had good reasons to believe that Mrs. Erickson did not want to have surgery, then perhaps his belief would have some merit. Depending on the state where this case occurs, there may be laws prohibiting treatment decisions based on perceptions of a patient's quality of life that are not specifically directed or indicated by the patient. Wisconsin law, for example, prohibits the withholding or withdrawal of effective life-sustaining treatment unless the patient is in a persistent vegetative state, has clearly known preferences to forgo such treatment, or has appointed a power of attorney for health care [3].

Based on this understanding of Mrs. Erickson's case, we would make five broad recommendations:

- Clarify Mrs. Erickson's granddaughter's decision-making authority and include Mrs. Erickson in treatment discussions to the extent that she is able to participate.
- Given the lack of clarity about Mrs. Erickson's current treatment preferences, immediate treatment decisions should be based on medical necessity. Mrs. Erickson's treatment team should consult with the cardiothoracic surgery team to determine both the feasibility and urgency of surgery; if the surgery team recommends against surgery, it should be explained to Mrs. Erickson and her granddaughter why surgery is not a viable therapeutic option. In making a recommendation about surgery, the surgery team should consider whether surgery will help sustain Mrs. Erickson's life or merely prolong her dying process.
- If surgery is a viable option and is urgently needed, Mrs. Erickson should receive the surgery since we cannot say with certainty that she would not want it. However, if surgery is not urgent and there is time to explore Mrs. Erickson's treatment preferences further, surgery should be withheld as long as needed to explore her treatment preferences. The treatment team should attempt to identify whether there are others who know Mrs. Erickson—e.g., friends, nursing home residents, or staff—who may have had specific discussions with her while she was cognizant or who might be able to offer insight into her values or goals of care to help clarify her treatment wishes.
- If surgery is not a viable option, the treatment team should consider other treatment options including the possibility a comfort-only focus, in which treatment is offered with a purely palliative intent. If available, the treatment team should consider consulting with their affiliated palliative care or hospice providers.
- The resident concerned about offering surgery to Mrs. Erickson should bring this instance of poor advance care planning to the attention of the quality department or ethics committee and help them redesign the system so that it becomes part of the institutional culture to routinely update and rediscuss patients' preferences, particularly when new, progressive health conditions

are diagnosed or when these conditions might affect the long-term capacity of patients to make their own health decisions.

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Commentary 2

by Meera Balasubramaniam, MD, MPH, and Yesne Alici, MD

At the outset, this might appear like a straightforward situation of implementing what the patient has specified in her advance directive, but critical elements of this case raise ethical dilemmas for both the care team and Mrs. Erickson's granddaughter. Firstly, it is important to note that Mrs. Erickson's advance directive was prepared 15 years ago, when her medical condition consisted only of mild, well-controlled hypertension. More importantly, she is reported to have been significantly more independent and capable than at the present. Secondly, while we are informed that the granddaughter, Caitlin, is her next of kin, Caitlin and her grandmother have not discussed end-of-life care, so her lack of awareness of Mrs. Erickson's goals and values is of concern.

Guidelines and Recommendations

Decision-making capacity. It is paramount to first determine whether Mrs. Erickson has the capacity to make a decision regarding her treatment. This is critical, because advance directives or surrogate decision makers come into play only if the patient lacks capacity. Miller and Marin's formulation for determining decision-making capacity consists of the following questions: (a) Do the history and physical

examination confirm that the patient can communicate a choice? (b) Does the patient understand the essential elements of an informed consent? (c) Can the patient assign personal values to the risks and benefits of an intervention? (d) Can the patient manipulate the information rationally and logically? (e) Is the patient's decision-making capacity stable over time [1]?

While individual clinicians may vary in the specific questions they ask a patient, it is recommended that the elements of understanding, appreciation, reasoning, and expressing a choice be covered for each decision made, for a person may have the capacity to make one decision but not another [2]. Although cognitive impairment impacts one's ability to understand and express, it does not automatically preclude decision-making capacity. Sessums and colleagues demonstrated that the mini-mental status exam (MMSE) correlates with capacity or incapacity only in extreme scores [3]. Palmer and colleagues identified the ability to conceptualize, initiate, and persevere on a thought as key factors indicating capacity to appoint a proxy, while memory was a significant predictor of capacity to consent to a neurosurgical clinical trial [4].

We recommend first discussing her medical situation thoroughly with Mrs. Erickson. This ought to include details of her medical condition, the goals of treatment, description of the available treatment options, the prognosis of her condition in the case of each treatment option, the chances of success and risks involved in the case of each treatment modality, the expected quality of life related to each option offered. She should be allowed the opportunity to ask questions. After this discussion, the next step would be assessing Mrs. Erickson for her capacity to make a decision regarding whether or not she wants to undergo aortic valve replacement. If an attending physician determines that Mrs. Erickson has the capacity to make a decision regarding the proposed surgery, the decision she makes at this time should be honored, irrespective of whether it is consistent with the advance directive. This would be served best in a multidisciplinary team meeting, with her granddaughter present, if Mrs. Erickson desires. It would also be good to revisit Mrs. Erickson's advance directive now if she possesses the capacity to do so.

Should Ms. Erickson be deemed to lack capacity, we recommend following the hierarchical decision-making procedure proposed by Buchanan and Brock, in which the advance directive follows patient decision making and is followed by substituted judgment and best interest in subsequent steps [5].

Advance directive. The directive came into being with the primary objective of protecting individual autonomy. The document's title, its constituent parts, and the procedure by which it is prepared vary from state to state. It broadly consists of two parts and may document a person's wishes about life-sustaining treatment (living will), choice of a surrogate decision maker (durable power of attorney for health care), or both.

Mrs. Erickson has an advance directive in which she specified that she would like to receive all available medical interventions. However, there is no mention of whether the advance directive has been discussed, revisited, or modified since its formulation. Anticipating future medical situations and predicting what one's preference at that time might be are challenging. One study found that preferences about life-sustaining treatments changed in one-third of individuals over a two-year period [6]. Gready and colleagues have discussed that most individuals do not have insight and awareness into how their preferences change over time and may not modify the advance directives to reflect these changes [7].

One could assume that following what Mrs. Erickson stated in her advance directive would be the clearest way of respecting her autonomy. However, the age of the document and the disparities in her medical and functional status between the time her advance directive was drawn up and the present raise important questions about whether her best interests would indeed be served by uncritically following the document. Another factor that merits consideration is whether the directive covers the current clinical situation. For example, although directives of "do not resuscitate" and "do not intubate" are considered similar by clinicians, individual patients might not view them as the same. For this reason, it is appropriate to involve the family in the patient's care, even if the advance directive is unambiguous.

Smith and colleagues proposed a framework for striking a balance between previously expressed preferences and what might serve best interests at the present time. The factors they considered were how emergent the clinical situation is, the risk-benefit ratio of implementing versus withholding interventions, how well the advance directive fits the situation, the leeway provided by the patient to the surrogate for overriding the advance directive, and the team's assessment of how well the surrogate represents the patient's best interests [8]. Jonsen and colleagues recommended decision making based on four broad themes, namely, the medical indications, respect for patient autonomy, quality of life, and contextual factors, including but not limited to religious, financial, and legal considerations [9].

Based on the approach recommended by Smith and colleagues, we can state that our patient is faced with an important clinical problem, but one that is not an emergency and that affords the opportunity for careful deliberation. An advance directive is present but is an ambiguous fit with the current circumstances. We do not know of any leeway provided in the directive. The granddaughter, although identified as the next of kin, is young and has not engaged in end-of-life discussions with her ailing grandmother. Of note, whether and to what extent a surrogate decision maker can override what has been stated in the advance directive depend on state law.

Surrogate decision making. If a patient lacks decision-making capacity and the applicability of the directive is dubious, a surrogate decision maker's input may help in developing an accurate reflection of the patient's wishes. There are two approaches to surrogate decision making, namely "substituted judgment" and "best interest." In "substituted judgment," the surrogate "reports on" his or her knowledge

of the patient's preferences and values [10]. The "best interest" principle requires a surrogate to make a decision based on what he or she believes would best serve the patient's interests and well-being [5]. Of note, Braun and colleagues emphasize that the best interest principle should not presume that continuing life-sustaining treatment would necessarily serve a patient's best interest and encourage that a holistic approach to the patient's well-being be adopted [10].

If it is determined that Caitlin is making a decision, her feelings related to decision making should be discussed, for they can have an impact on whether the decision best serves the patient in question. Fritch and colleagues demonstrated that surrogate decision making is influenced by patient factors (input at the present time, past knowledge of values and best interest) and surrogate factors (the use of surrogate's own wishes as a guide, religious beliefs, the surrogate's own interests, family consensus, and feelings of obligation and guilt) [11]. The physician should be open to have an ongoing conversation with Caitlin throughout the course of Mrs. Erickson's treatment.

The medical community will be faced with an increasing number of such ethical dilemmas in the future, with the simultaneous advancement in technology to prolong life and the increase in the prevalence of individuals with dementias. As physicians, we will be serving our patients well by having discussions on advance directives early and revisiting them regularly. We also recommend that all physicians familiarize themselves with the federal and state statutes on decision making and involve consultation liaison psychiatry, the ethics team, or hospital's legal counsel, if needed, in complicated cases.

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