
CLINICAL ETHICS | CASE CONSULTATION

This document is designed to support discussion and evaluation of clinical cases brought to an ethics committee for review. It includes a case summary, a review of the pertinent ethical considerations, and a brief literature review.

CASE SUMMARY¹

Mrs. Barnes, 77, suffers from chronic obstructive pulmonary disease (COPD), peripheral vascular disease, and early dementia. For the last six years she has lived in a nursing home, where her medical condition has remained fairly stable. Although her cognitive status has gradually declined, she has been able to interact with her family, her caregivers, and other residents. She has also been able to make simple decisions about her daily activities.

Mrs. Barnes has recently complained of chest pain and shortness of breath. These symptoms coincided with a change in her mental status, becoming more confused and agitated. She was admitted to the hospital where tests revealed that she had suffered a mild heart attack and was in acute renal failure. Her attending physician and a renal consultant recommended a few dialysis treatments to: (1) treat her kidneys, (2) potentially improve her mental status, and (3) give clinicians time to assess the extent of her heart damage.

When Mrs. Barnes initially entered the nursing home, she completed a living will, which includes a statement indicating she would not want dialysis if she were terminally ill or permanently unconscious. She also completed a health care proxy document, appointing her daughter, Carol, as her primary agent, and her son, Philip, as her secondary agent.

Mrs. Barnes' current mental state has left her unable to make her own care decisions or to provide informed consent. Her primary health care proxy, Carol, has consented to the dialysis. Philip, however, believes that dialysis would violate their mother's living will. Carol has said, "If Mom had known that temporary dialysis might improve her condition, especially while we are waiting to see about her heart, she certainly would have agreed to that. What she never wanted was to be dependent on long-term dialysis or to have it just prolong her dying."

An ethics consult has been requested to help resolve the conflict.

¹ The case discussed in this document is adapted from: Post, L. F. & Blustein, J. (2015). *Handbook for health care ethics committees*, p. 282. Baltimore, MD: Johns Hopkins University Press.

ETHICAL CONSIDERATIONS

AUTONOMY: Honoring the instructions in a living will is a vital means by which patients maintaining self-determination in the event they are no longer competent to make decisions for themselves. While Mrs. Barnes' living will states that she would not consent to dialysis "if she were terminally ill or permanently unconscious," the document does not address how she would approach dialysis if she were *not* terminally ill or permanently unconscious. Since further clinical assessments are necessary to determine whether Mrs. Barnes is likely to recover from this health episode, the provision in the living will prohibiting dialysis may not apply to the patient's current condition.

INTENTION: The lack of clarity regarding Mrs. Barnes' prognosis, combined with the imprecise language of her living will, calls into question what Mrs. Barnes intended when she chose to decline dialysis. The care team must rely on the insights of her health care proxy, her daughter Carol, who should be trusted to make the decision the patient would if she were able. The ethics committee should consider how to best explain Carol's role and authority to all parties so that trust between the care team and the family can be maintained.

FAMILY-CAREGIVER RELATIONS: The disagreement between Mrs. Barnes' children/proxies potentially places the hospital's medical team in the middle of a family conflict with unknown repercussions. The ethics committee and hospital administration should be mindful of their duty to ensure that the hospital is a safe environment for caregivers as much as it is for patients. Some consideration may need to be paid to whether the doctors, nurses, or other specialists involved are experiencing moral distress, whether they are being asked to take sides, and what support they may need while the disagreement between health care proxies is being resolved.

LITERATURE REVIEW | LIMITATIONS OF THE LIVING WILL

There are two schools of thought regarding the usefulness and applicability of living wills and advance directives. Fagerlin & Schneider (2004), for example, argue that the living will is a failed experiment that should be abandoned. The authors claim that five conditions must all be met for a living will to be successful (p. 32):

1. A person must have a living will;
2. The person must have a full understanding of the range of treatments she/he would or would not want in the event of incompetence;
3. She/he must be able to accurately express those instructions;
4. The living will must be made available to surrogates and health care providers; and
5. The surrogates and providers must be able to understand the instructions.

We can certainly see the evidence of some of these failures in the case of Mrs. Barnes. While she does have a living will and has made it available to all relevant parties, she could not have anticipated her current situation and thus the language in the document has left her proxies without a clear path.

On the other side of the debate, Levi & Green (2010) have argued that the problem with living wills and advance directives lay in the process, not the document itself. They have devised a computer-based decision aid that engages people in “the kind of in-depth dialogue that is at the heart of advance care planning” (p. 7). Their tool culminates in an advance directive that articulates both treatment preferences and the person’s values so that surrogates understand the overarching priorities that should be considered when unanticipated circumstances arise. While it is obviously too late for Levi & Green’s (2010) online decision aid to be applied to Mrs. Barnes, it may be worthwhile for the ethics committee and hospital administration to evaluate its usefulness with the intention of advocating its broader use.

References

- Fagerline, A. & Schneider, C.E. (2004). Enough: The failure of the living will. *Hastings Center Report* 34(2), 30-42.
- Levi, B.H. & Green, M.J. (2010). Too soon to give up: Re-examining the value of advance directives. *The American Journal of Bioethics*, 10(4), 3-22.
- Post, L. F. & Blustein, J. (2015). *Handbook for health care ethics committees*. Baltimore, MD: Johns Hopkins University Press.