The Invalid Advance Directive

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Advance directives, when they stipulate that specific treatments be withdrawn or withheld, often fail to match the signer's more nuanced situation-based oral instructions. Nevertheless, they remain powerful documents that, when constructed and administered carefully, can direct decision making in end-of-life care.

Advance directives are a central intervention to improving advance care planning in the United States. Widely available, these documents can be useful clinical tools for fostering communication between patients, surrogates, and physicians. They may provide guidelines for future decisions, thereby reducing the burden of difficult decision making on surrogates and family members. However, they are imperfect tools, capable of creating disastrous outcomes when used improperly. The following case of a fifty-five-year-old female with metastatic ovarian cancer illustrates this point.

The woman's medical treatment at a tertiary care medical center had been extensive, involving repeated laparoscopies, multiple courses of chemotherapy, and blood transfusions. On the day of hospital admission, the patient vomited a large amount of blood. In the emergency room, she was alert and oriented but her blood count was extremely low and she was continuing to bleed from an upper gastrointestinal source. She was emergently transfused.

The patient brought her Durable Power of Attorney for Health Care with her to the emergency room, just as she had during each of her previous hospitalizations. The document had been professionally prepared by her lawyer, who had also drafted divorce papers and a will at the time of the patient's cancer diagnosis. The advance directive named her sister as her agent. The document was signed by the patient and two unrelated witnesses. Neither the patient's attending physician nor the sister were aware of the advance directive.

The document further identified the patient's desires to:

> refuse life prolonging procedures ... including (but not limited to) cardiopulmonary resuscitation, the implantation of a cardiac pacemaker, renal dialysis, parenteral feeding, the use of respirators or ventilators, blood transfusions, naso-gastric tube use, intravenous feedings, endotracheal tube use, antibiotics, and organ transplants ... You may specifically request and concur with the writing of a "no-code" (do not resuscitate) order by the attending or treating physician.

After reading the document, the physician in the emergency room discussed incongruencies between immediate treatment plans and the wishes expressed in the patient's advance directive. The patient stated she was unaware of the details, never having read the document carefully. She said her wishes were to avoid life in a persistent vegetative state, but she wanted to continue the aggressive treatment plan to combat her cancer, including chemotherapy, repeat laparotomies, and cardiopulmonary resuscitation as needed. The document was amended in the emergency room to reflect her wishes. The patient intended to rewrite the advance directive after hospital discharge.

If this patient had become unconscious in the emergency room and her advance directive had been followed, the implications would have been confusing, if not disastrous. She had not discussed the content of her advance directive with her physician or with the named surrogate decision maker. Therefore, the potential medical decision makers who might have known her preferences in order to contradict the written document would have been unable to do so. Fortunately, the patient was conscious and able to recant her advance directive when it was reviewed in the emergency room.

Advance directives are useful for specifying who should be the surrogate decision maker when an individual loses the ability to make decisions. This is particularly important for patients without family, patients with families in conflict, and patients for whom the appropriate surrogate is unclear. In the case cited, the patient completed an advance directive specifying her sister as her agent. Because of her divorce at the time of the cancer diagnosis, the patient felt it would not have been clear to whom she would turn should she have had a catastrophic event early in her cancer treatment.

In addition to naming an agent, advance directives may communicate actual treatment references, although only a small proportion of such documents do so. In theory, these specifications may guide care decisions. However, data from SUPPORT suggest that such written instructions rarely direct specific care decisions (Teno et al. 1997).

As shown in the case presented, even when advance directives include treatment decisions, these decisions may not guide care. To be effective, advance directives must accurately state patients' wishes and be usable within the logistic constraints of clinical practice (Emanuel and Emanuel 1995). Advance directives are susceptible to many errors that may affect their validity. Patients often do not understand their prognosis and may inaccurately estimate the chance of therapeutic success. Patients also substantially overestimate the efficacy of CPR (Miles, Koep, and Weber 1996). Patients' preferences are significantly influenced by physician preferences and clinical descriptions of expected outcomes (Murphy, Burrows, and Dantilli 1994).

If advance directives are to play an important role in end-of-life care, they must be created and reviewed carefully, with both patients and physicians attending to content, accuracy, and validity.

The case presented here, in which an advance directive does not actually reflect the patient's preferences, teaches the importance of the way an advance directive is administered. These are not undifferentiated documents with blanks to be filled in. Specification of preferences often requires that the patient understand the diagnosis and have some information about prognosis and possible responses to therapy. Treatment preferences not stated in that context are unlikely to reflect a patient's clinical situation or authentic wishes. When such documents are prepared by lawyers, care must be taken to match the ideas dictated in the document with clinical reality.

Secondly, when discussing advance care planning with their patients, clinicians need to ask whether patients have completed advance directives. While physicians have not adopted the practice of routinely discussing advance directives and preferences, the question whether a patient has a directive easily can be integrated into practice.

Last, this patient was admitted to the hospital numerous times before the admission discussed here. During prior admissions, care included ventilator use and transfusions. This care was

consistent with the patient's preferences but was in violation of the advance directive (that was not in effect). If these documents are not read, they cannot be used to stimulate discussion of future care and preferences. More important, an unread document can lead to care contrary to the patient's preferences or, at a minimum, to both clinician and family discomfort about making decisions contrary to a patient's stated preferences.

Conclusion

While advance directives may not have revolutionized end-of-life decision making, they remain powerful documents that can direct decision making and even specify treatments for individual patients. These documents must be constructed and administered carefully, with attention to the patient's capacity to complete such a document and the patient's understanding of the decisions contained in the document (Wenger and Halpern 1994). Just as a poorly constructed financial will would not be tolerated, neither should patients or clinicians accept less than full accuracy and validity in a health care advance directive. If advance directives are to play an important role in end-of-life care, they must be created and reviewed carefully, with both patients and physicians attending to to content, accuracy, and validity.

References

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