

AMA CODE SAYS

AMA Code of Medical Ethics' Opinions Related to Unrepresented Patients

Danielle Hahn Chaet, MSB

Abstract

The AMA *Code of Medical Ethics* offers guidance on decision making for unrepresented patients in Opinion 5.2, "Advance Directives." This opinion discusses situations in which a surrogate is needed because the patient is unable to make his or her own health care decisions, but none is available.

Generally, patients are free to exercise autonomy in making decisions about their health care. However, as I have written elsewhere, "not all patients have capacity (a clinical standard applying to a particular decision at a particular point in time) or competence (a legal standard applying to all decisions at all times)" to make these choices.¹ The American Medical Association (AMA) *Code of Medical Ethics'* Opinion 2.1.2, "Decisions for Adult Patients Who Lack Capacity," notes that "When a patient lacks decision-making capacity, the physician has an ethical responsibility to ... identify an appropriate surrogate to make decisions on the patient's behalf." Ideally, this person is designated by a patient "as surrogate through a durable power of attorney for health care or other mechanism."²

When patients lack identification, documentation, family, or other support systems, they might be homeless, elderly, or incarcerated. If and when these patients lose decision-making capacity, they become a class of patients we've come to regard as unrepresented. Unrepresented patients might be unrepresented for a short time (as in [an emergency](#), before an identification is able to be made or a surrogate secured) or terminally. Opinion 5.2, "Advance Directives," provides guidance applicable to these first stages of care. It states: "In emergency situations when a patient is not able to participate in treatment decisions and there is no surrogate or advance directive available to guide decisions, physicians should provide medically appropriate interventions when urgently needed to meet the patient's immediate clinical needs."³ If the patient's preferences become known at a later date, interventions may be withdrawn in accordance with those preferences and "ethics guidance for withdrawing treatment."³

If no surrogate is ever identified, a physician may turn to state or local courts to initiate [guardianship proceedings](#). At other times, a health care professional familiar with the case may make decisions for the patient.⁴ In any case, the ethical complexity of caring for

a patient about whom little, if anything, is known is amplified in end-of-life care decisions. Opinion 2.1.2 states that decisions should be made “in keeping with the best interest standard when the patient’s preferences and values are not known and cannot reasonably be inferred.”² The opinion specifies that the following should be taken into account in best interest decisions:

1. The pain and suffering associated with the intervention
2. The degree of and potential for benefit
3. Impairments that may result from the intervention
4. Quality of life as experienced by the patient²

It can be difficult for a guardian, when one can be secured, or a care team to ascertain what is in a patient’s best interest, particularly since patients who lack decision-making capacity and representation are vulnerable due, in part, to their anonymity and aloneness. The AMA *Code* reminds us that ethics committees or other institutional resources can be helpful in difficult cases, such as those involving unrepresented patients.²

References

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Danielle Hahn Chaet, MSB is a research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago, Illinois. Her work involves researching, developing, and disseminating ethics policy and analyzing current issues and opinions in bioethics. She obtained her master of science degree in bioethics, with a focus on clinical policy and clinical ethics consultation, from the joint program of Union Graduate College and the Icahn School of Medicine at Mount Sinai.

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