

HEALTH LAW

Five Things Clinicians Should Know When Caring for Unrepresented Patients

Thaddeus Mason Pope, JD, PhD

Abstract

Increasingly, clinicians confront patients who are incapacitated and have no available surrogate. Such unrepresented patients cannot consent to proposed health care, and nobody else is available who is authorized to consent on their behalf. Despite the challenge of decision making for unrepresented patients, few laws or professional organization policy statements offer a solution. This article helps fill this void by describing the top 5 things clinicians should know when they are caring for unrepresented patients: (1) realize that these patients are highly vulnerable; (2) confirm that the patient is incapacitated; (3) confirm that the patient is unrepresented; (4) appreciate variability among state law decision-making processes for unrepresented patients; (5) use guardianship only as a last resort.

Five Things Clinicians Should Know

If a patient in a health care organization is incapacitated and has no available surrogate, this means that the patient cannot consent to proposed health care and that nobody else is available who is authorized to consent on the patient's behalf. Decision making for such unrepresented patients is a common challenge in the United States. Nevertheless, few laws or professional organization policy statements address either who should make treatment decisions for unrepresented patients or according to which criteria treatment decisions should be made.¹⁻³

To provide actionable recommendations in the absence of formal guidance, this article describes the top 5 things that clinicians should know when caring for unrepresented patients. First, clinicians should realize that unrepresented patients are highly vulnerable. Second, clinicians must confirm that the patient is, in fact, incapacitated. Third, clinicians must confirm that the patient is, in fact, unrepresented. Fourth, clinicians should appreciate that [state law](#) decision-making processes for unrepresented patients are highly variable. Fifth, clinicians should use guardianship and conservatorship only as a last resort.

Unrepresented Patients Are Highly Vulnerable

Unrepresented patients are extremely vulnerable. They not only are unable to advocate for themselves but also lack trusted and reliable friends or family to advocate for them. As such, clinicians and institutions should carefully evaluate treatment decisions made on their behalf.³ Unrepresented patients face 3 types of treatment risks: overtreatment, undertreatment, and delayed treatment.

Overtreatment. The absence of an authorized surrogate often results in maximum medical intervention whether clinically and ethically warranted.³ There are several reasons why unrepresented patients receive unnecessary or unwanted treatment, including: (1) clinicians' fear of not providing appropriate treatment, (2) clinicians' fear of civil liability for failure to treat, (3) institutional fear of regulatory sanctions, (4) clinicians' economic incentives to treat, and (5) clinicians' general interventionist philosophy of medicine.³

Undertreatment. Whereas most unrepresented patients are overtreated, some are undertreated. With no surrogate to object, some clinicians may decide that treatment is inappropriate and unilaterally withhold or withdraw it. Other clinicians may refuse to provide any type of treatment without informed consent. Consequently, important decisions may be postponed or forgone altogether.³

Delayed treatment. Finally, some clinicians will wait until [an emergency](#) when consent is implied and there is no need for a surrogate to authorize treatment. However, waiting for an emergency may result in longer periods of suffering and indignity, increasing the chance of patient morbidity or mortality. Addressing the issue of unrepresented patients, the Institute of Medicine found it ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied."⁴

In short, available evidence suggests that, in the absence of a surrogate, there is a risk that incapacitated patients will receive treatment inconsistent with their preferences or best interests. Being aware of these risks should help clinicians be more vigilant in guarding against them.

Confirm That the Patient Is, in Fact, Incapacitated

The core challenge in decision making for an unrepresented patient is identifying who can make health care decisions for the patient when she cannot make them for herself. As long as the patient retains decision-making capacity, she can make her own health care decisions. And as long as the patient can understand the significant benefits, risks, and alternatives and can make and communicate a decision about proposed health care, there is no need for a surrogate. Unfortunately, clinicians might too quickly (and erroneously) conclude that a patient lacks capacity.

Three tips should help mitigate such errors in determining capacity. First, all patients are presumed to have capacity. Therefore, it is not the clinician's job to *prove* that the patient has capacity. Instead, it is the clinician's job to rebut the presumption and prove that the patient lacks capacity. Second, capacity is a decision-specific determination. Just because the patient lacks capacity to make more complex decisions (like surgery) does not necessarily mean that the patient also lacks capacity to make simpler decisions. Importantly, the patient may retain the ability to designate a surrogate. Third, decision-making capacity is often not a fixed state. It may fluctuate over time, such that the patient has capacity in the morning but not in the afternoon. Moreover, even if the patient lacks

decision-making capacity, clinicians should restore it to the extent possible (for example, by trying alternative pain management medications).⁵

In short, clinicians should always assess capacity carefully. Except in cases of obvious and complete incapacity, clinicians should always attempt to ascertain the patient's ability to participate in the decision-making process.^{6,7} The best decision maker for the patient is the patient herself. Clinicians should not turn to substitutes and alternatives unless necessary.

Confirm That the Patient Is, in Fact, Unrepresented

If the patient is, in fact, incapacitated, then a [surrogate](#) must make health care decisions on the patient's behalf. Unfortunately, just as clinicians might too quickly conclude that patients lack capacity, they might also too quickly (and erroneously) conclude that patients lack available surrogates. Patients who appear to be unrepresented are often not, in fact, unrepresented.³

Three tips should help mitigate errors in determining whether patients are unrepresented. First, clinicians should make diligent efforts to ascertain if the patient has an advance directive or [physician order for life-sustaining treatment](#). If the patient has written wishes, instructions, or orders, then those documents should guide health care decisions. In rare cases, these documents may be sufficiently clear and applicable to preclude the need for a surrogate. Second, clinicians should make diligent efforts to locate available surrogates. Social workers have a rich toolkit of strategies that often prove successful; a thorough search will usually locate a surrogate.⁵ Third, clinicians should take a broad and flexible view of who can serve as the patient's surrogate. Many state default surrogate statutes specify a short, limited list of surrogate categories, usually in a priority sequence (eg, spouse, adult child, adult sibling).³ If nobody on this list is available, clinicians should consider consulting people who know and care about the patient, even if they do not fit into categories on the statutory list.

State Laws on Unrepresented Patients Are Highly Variable

While only a dozen states have formally specified decision-making processes for unrepresented patients, those state processes are highly variable.³ For example, in the absence of an available surrogate, Nebraska and North Carolina permit the attending physician to make life-sustaining treatment decisions on the patient's behalf.³ In contrast, other states require various levels of vetting and oversight for these decisions. For example, Arkansas and Tennessee require consultation with or concurrence from a second independent physician; Florida requires an independent clinical social worker for decisions about major medical treatment; and Colorado and Montana require the approval of a medical ethics committee for end-of-life treatment decisions.³

Clinicians should view these laws as a floor rather than as a ceiling. Because of the vulnerability of unrepresented patients, institutions in these and other jurisdictions should manage decision making through a fair process even when state law authorizes procedures with less oversight. Typically, more oversight is warranted as the invasiveness or burden of

the treatment increases. Some hospital policies divide treatment into 3 categories: (1) routine medical treatment, (2) major medical treatment, and (3) life-sustaining treatment.⁸⁻
¹⁰ At least with respect to life-sustaining treatment, clinicians should consult a multidisciplinary committee even if not required by law.

Use Guardianship and Conservatorship Only as a Last Resort

As I have written elsewhere, “Guardianship is a legal relationship that is created by state courts when a judge determines that the patient is incapacitated and unable to make decisions on their own behalf. The court creates a relationship in which the guardian is given legal authority to make decisions for an incapacitated individual.”³ In most states, guardianship (also known as conservatorship) remains the only officially recognized mechanism by which treatment decisions can be made on behalf of the unrepresented.

At first, guardianship looks like a good solution. The formal judicial process helps ensure neutrality, impartiality, and public accountability. But, as I have written elsewhere, guardianship is generally considered “neither a preferred nor an adequate solution.”³ Both legal and medical commentators “have overwhelmingly concluded that the disadvantages of guardianship significantly outweigh the advantages.”³ The process is slow and expensive. And it is often ineffective, either because a guardian cannot be found or because the guardian has real or perceived constraints on his or her ability to make decisions in the patient’s best interest. “Consequently, guardianship is generally considered to be a last resort option, to be used only after all other less restrictive alternatives have been exhausted.”³

Conclusion

While the challenge of decision making for unrepresented patients has been documented for decades, there is still no consensus on the proper solution. Few legislatures, regulators, or professional societies have developed laws or policies to adequately protect this vulnerable population. Worse, the few laws and policies that exist are inconsistent and variable in terms of the oversight required for treatment decisions. Therefore, the main contribution of guidelines is likely to be at the institutional level.

References

1. Pope TM. Making medical decisions for patients without surrogates. *N Engl J Med*. 2013;369(21):1976-1978.
2. Pope TM. Legal fundamentals of surrogate decision making. *Chest*. 2012;141(4):1074-1081.
3. Pope TM. Unbefriended and unrepresented: medical decision making for incapacitated patients without healthcare surrogates. *Ga State Univ Law Rev*. 2017;33(4):923-1019.
4. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press; 2015.

5. Moye J, Catlin C, Kwak J, Wood E, Teaster PB. Ethical concerns and procedural pathways for patients who are incapacitated and alone: implications from a qualitative study for advancing ethical practice. *HEC Forum*. 2017;29(2):171-189.
6. Miller TE, Coleman CH, Cugliari AM. Treatment decisions for patients without surrogates: rethinking policies for a vulnerable population. *J Am Geriatr Soc*. 1997;45(3):369-374.
7. Farrell TW, Widera E, Rosenberg L, et al; Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society. AGS Position statement: making medical treatment decisions for unbefriended older adults. *J Am Geriatr Soc*. 2017;65(1):14-15.
8. Decision-making for unrepresented patients. Thaddeuspope.com. http://thaddeuspope.com/images/Unrepresented-Patients-1_SOCAL_BIOETHICS.pdf. Accessed May 22, 2019.
9. Cleveland Clinic policy on medical decision-making for patients lacking decision making capacity who do not have a surrogate decision-maker. Thaddeuspope.com. http://thaddeuspope.com/images/CLEVELAND_CLINIC_Policy_on_Patients_with_out_Surrogates_a.pdf. Published April 20, 2009. Accessed May 22, 2019.
10. Stanford Hospital and Clinics. Health care decisions for patients who lack capacity and lack surrogates. Thaddeuspope.com. http://thaddeuspope.com/images/Stanford_Health_Care_Decisions_For_Patients_Who_Lack_Capacity_and_Surrogates_7_09.pdf. Published July 2009. Accessed May 22, 2019.

Thaddeus Mason Pope, JD, PhD is a professor of law at the Mitchell Hamline School of Law in Saint Paul, Minnesota, where he is also the director of the Health Law Institute. His 200 publications include, with Alan Meisel and Kathy L. Cerminara, *The Right to Die: The Law of End-of-Life Decisionmaking* (Wolters Kluwer, 2019) and the *Medical Futility Blog*. His scholarship focuses on using the law to improve medical decision-making and to expand choices at the end of life.

Citation

AMA J Ethics. 2019;21(7):E582-586.

DOI

10.1001/amajethics.2019.582.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2019 American Medical Association. All rights reserved.
ISSN 2376-6980**