

## FROM THE EDITOR

### Representing Unrepresented Patients

Holland M. Kaplan, MD

I recently cared for a debilitated, elderly man who had not been provided with any water to drink for over 2 weeks. He was admitted to the hospital with confusion and was found to have a sodium level of 180 mEq/L, a value I did not know was compatible with life. As we treated him, it became apparent that even after his sodium level had returned to normal, he was not going to be able to swallow or meaningfully communicate with those around him. As an internal medicine resident, I spend a lot of time with patients and their families discussing goals of care. Thankfully, we were able to have extensive conversations with this patient's son about what his father would have wanted had he been able to make decisions. We were ultimately able to discharge him on home hospice, confident that this decision was consistent with what he would have wanted.

Unfortunately, some patients do not have any family, friends, or documentation to help guide their care. This theme issue of the *AMA Journal of Ethics* addresses the complex challenges of who should make decisions for unrepresented patients and considers values that should inform these decisions.

Health care professionals frequently care for unrepresented patients. One study found that 16% of patients in an intensive care unit (ICU) were unrepresented,<sup>1</sup> and another found that 5.5% of ICU deaths occur in unrepresented patients.<sup>2</sup> Moreover, one-third of surveyed physicians who care for critically ill patients admitted to withdrawing life-sustaining treatment in unrepresented patients.<sup>3</sup> Given how common it is to care for these patients, health care professionals must have an understanding of potential ethical and legal questions arising in the care of unrepresented patients.

Unrepresented patients lack decision-making capacity, an advance directive, and a surrogate decision maker. These patients cannot make their values and preferences known, and thus we are tasked with making decisions on their behalf. Unrepresented patients commonly include those who are elderly, homeless, incarcerated, and mentally disabled,<sup>4</sup> and contributors to this issue examine these and other groups. David Ozar discusses the characteristics and conditions of unrepresented patients as defined by the [Unrepresented Patient Project](#) for Illinois. Giselle Malina examines how medical decisions are made for [children in immigration detention](#) without informed consent. And Matthew Tobey and Lisa Simon explore the challenges of choosing surrogates for and making decisions on behalf of [unrepresented inmates](#), a particularly underserved population.

A variety of surrogates are called upon to make decisions for unrepresented patients. A court may assign an unrepresented patient a guardian. However, the minimal qualities of an acceptable guardian have been described by one clinician interviewee as “someone who answers the phone and visits once per quarter,”<sup>5</sup> and important medical decisions often must be made during the prolonged process of appointing a guardian.<sup>6</sup> Lisa K. Anderson-Shaw examines difficulties with the [legal guardian system](#) and proposes a patient advocacy committee as a potential alternative. And Scott J. Schweikart discusses variations of a “[tiered approach](#)” involving multiple levels of medical risk and multiple parties in making decisions on behalf of unrepresented patients.

There are a number of reasons for concern about the degree to which physicians should be involved in decision making for unrepresented patients. There is evidence that physicians are unable to accurately predict patients’ preferences.<sup>7</sup> Nevertheless, at one hospital, they made treatment decisions in 77% of ICU cases involving unrepresented patients.<sup>8</sup> Such physician involvement could lead to unwarranted variation in treatment,<sup>8</sup> raising justice-based concerns. Physicians’ dual commitment to individual patients and society as a whole<sup>9</sup> also suggests a possible conflict of interest. Additionally, physicians are more likely than the general public to believe that life-sustaining treatment should be withdrawn in the case of a critically ill patient.<sup>10</sup> Several contributors offer recommendations for caring for unrepresented patients. Timothy M. Dempsey and Erin Sullivan DeMartino suggest implementing a [standardized process](#) to make decisions on behalf of unrepresented patients that mitigates any potential institutional and clinician bias. Thaddeus Mason Pope provides clinicians with [practical guidance](#) on caring for patients who appear to be incapacitated and unrepresented. Finally, in his winning essay for the John Conley Ethics Essay Contest, Ryan G. Chiu argues that physicians have an [ethical obligation](#) to document, disclose, and rectify errors in cases of unrepresented patients.

A novel approach to discerning an unrepresented patient’s wishes involves using patient preference predictors, complex models that incorporate the decision-making tendencies of certain groups (eg, based on age, race, gender) to determine how a patient might have responded in a given situation. But these models raise ethical concerns about stereotyping and how they are constructed.<sup>11-13</sup> Nathaniel Sharadin discusses ethical implementation of [patient preference predictors](#) and 3 types of problems that might arise with their use.

Legal guidance for making decisions on behalf of unrepresented patients varies regionally. For example, in Oregon physicians may withhold or withdraw life-sustaining treatment from unrepresented patients, whereas in Washington a guardian must be appointed to represent the patient’s interests.<sup>14</sup> Adira Hulkower, Sarah Garijo-Garde, and Lauren S. Flicker show how these [laws differ nationally](#) using the examples of New York

State and North Carolina. They also argue that the process by which treatment options are reached is as important to honoring the patient's wishes as the outcome itself.

As health care professionals, we often find ourselves in the unique, privileged position of being able to advocate for underserved patients. I hope that exploring the challenges of caring for unrepresented patients in this issue of the *AMA Journal of Ethics* will provide readers with tools to ethically and compassionately care for some of the most vulnerable members of our society.

## References

1. White DB, Curtis JR, Lo B, Luce JM. Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Crit Care Med*. 2006;34(8):2053-2059.
2. White DB, Curtis JR, Wolf LE, et al. Life support for patients without a surrogate decision maker: who decides? *Ann Intern Med*. 2007;147(1):34-40.
3. Asch DA, Hansen-Flaschen J, Lanken PN. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. *Am J Respir Crit Care Med*. 1995;151(2, pt 1):288-292.
4. Karp N, Wood E. Incapacitated and alone: health care decision-making for the unbefriended elderly. American Bar Association Commission on Law and Aging. [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2003\\_Unbefriended\\_Elderly\\_Health\\_Care\\_Descision-Making7-11-03.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2003_Unbefriended_Elderly_Health_Care_Descision-Making7-11-03.authcheckdam.pdf). Published July 2003.
5. Moyer 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. Bandy RJ, Helft PR, Bandy RW, Torke AM. Medical decision-making during the guardianship process for incapacitated, hospitalized adults: a descriptive cohort study. *J Gen Intern Med*. 2010;25(10):1003-1008.
7. Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Arch Intern Med*. 2001;161(3):431-440.
8. Pearlman RA, Inui TS, Carter WB. Variability in physician bioethical decision-making. A case study of euthanasia. *Ann Intern Med*. 1982;97(3):420-425.
9. ABIM (American Board of Internal Medicine) Foundation; ACP-ASIM (American College of Physicians-American Society of Internal Medicine) Foundation; European Federation of Internal Medicine. Medical professionalism in the new millennium: a physician charter. *Ann Intern Med*. 2002;136(3):243-246.

10. Rydvall A, Lynöe N. Withholding and withdrawing life-sustaining treatment: a comparative study of the ethical reasoning of physicians and the general public. *Crit Care*. 2008;12(1):R13.
11. Rid A, Wendler D. Use of a patient preference predictor to help make medical decisions for incapacitated patients. *J Med Philos*. 2014;39(2):104-129.
12. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med*. 2009;24(6):695-701.
13. Wendler D, Wesley B, Pavlick M, Rid A. A new method for making treatment decisions for incapacitated patients: what do patients think about the use of a patient preference predictor? *J Med Ethics*. 2016;42(4):235-241.
14. White DB, Curtis JR, Wolf LE, et al. Life support for patients without a surrogate decision maker: who decides? *Ann Intern Med*. 2007;147(1):34-40.

**Holland M. Kaplan, MD** is a second-year internal medicine resident at Baylor College of Medicine in Houston, Texas. Her interests include palliative care, end-of-life care, medical ethics, and medical decision making.

**Citation**

*AMA J Ethics*. 2019;21(7):E549-552.

**DOI**

10.1001/amajethics.2019.549.

**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.*