

## CASE AND COMMENTARY

### How Should Clinicians Navigate Decision Making for Unrepresented Patients?

Timothy M. Dempsey, MD, MPH and Erin Sullivan DeMartino, MD

#### Abstract

Caring for patients who lack decision-making capacity is common in health care and presents numerous practical and ethical challenges. Unrepresented patients are vulnerable in part because they do not have anyone to help articulate their values and preferences, and they cannot do so themselves. This commentary suggests a deliberative approach to responding to these patients' needs.

#### Case

Ms B is a 65-year-old homeless woman with 2 years of progressively worsening altered mental status, anxiety, depression, and paranoia. After several prolonged involuntary admissions at an inpatient psychiatric center, during which her altered mental status was refractory to multiple modalities of treatment, psychiatrists began to suspect an organic cause of her altered mental status and psychiatric symptoms. She was admitted to the hospital for further workup. During her hospitalization, she intermittently refuses tests and medications. She yells, "Get out!" to anyone who enters her room. All blood tests and imaging are negative. After consultation with neurology, it is determined that Ms B needs a lumbar puncture for further workup, which she consistently refuses. After a thorough assessment, the primary team determines that Ms B does not have capacity to refuse a lumbar puncture. No family members or friends have been identified during this hospitalization or during previous admissions at the inpatient psychiatric facility.

The primary inpatient physician, Dr C, is unsure about who should make decisions on Ms B's behalf and researches the hospital's guidelines and the recommendations of several professional organizations regarding unrepresented patients. She finds that the hospital has a process in place for assigning public guardians to patients. She discovers that the American Medical Association suggests consulting an ethics committee about making decisions on behalf of an unrepresented patient,<sup>1</sup> the American Geriatrics Society recommends that a patient's treatment team should make such decisions,<sup>2</sup> and the American College of Physicians posits that a court-appointed guardian should always be utilized.<sup>3</sup> Dr C wonders what to do.

## Commentary

The exact prevalence of hospitalized unrepresented patients is unknown, although one study found that 16% of patients admitted to an urban hospital's intensive care unit lacked decision-making capacity and were unrepresented.<sup>4</sup> Unrepresented patients are vulnerable by nature of their inability to make their own decisions and lack of a surrogate, and they can often be marginalized due to homelessness, being elderly, or having mental illness or substance use disorders,<sup>5</sup> all of which exacerbate their vulnerability. For all incapacitated patients, treatment teams should determine whether an advance directive names a durable power of attorney and, if not, work with a surrogate who is selected by a process that [varies from state to state](#).<sup>6,7</sup> In situations in which no surrogate is identified, such as in this case, health care professionals typically find diverse legal requirements that vary by jurisdiction.<sup>5</sup> For example, in some states, treating clinicians assume authority to make decisions for their unrepresented patients, but other states expressly forbid this practice.<sup>8</sup>

We suggest that health care organizations implement protocols to facilitate decision making for unrepresented patients based on professional guidelines and state law (where available) and on assessments of the risks and benefits of proposed treatments, particularly when care is provided despite a patient's objection. Unilateral decision making should be avoided in order to mitigate organizations' and physicians' potential conflicts of interest and biases. We advocate engaging multidisciplinary teams (such as ethics committees, when available) or volunteer advocates to assume decisional authority or at least contribute to decision making. But first we discuss issues in the care of unrepresented patients.

### Caring for Unrepresented Patients

*Respect patient autonomy.* Ms B intermittently accepts tests and procedures, suggesting fluctuating adherence to recommendations. Since Ms B is alert and sporadically cooperative with her care team, constant reassessment of her decision-making capacity is indicated, as it is important to recognize that capacity is decision specific and not "all or none." To express respect for the autonomy of an alert and verbal patient with diminished capacity, clinicians should encourage patients to articulate their wishes or fears or explain why they choose to decline suggested treatment. Insights gathered from these inquiries should be used to strengthen patient-clinician relationships and help develop personalized treatment plans for patients who might later lose decision-making capacity.

*Assess risks and benefits of treatment.* Risks and benefits of any treatment plan or intervention should be carefully evaluated. The procedure discussed in this case, lumbar puncture, carries relatively little risk, although conscious sedation might be necessary for the patient's and clinician's (given Ms B's resistance) safety and to maximize the procedure's chance of success. However, we should also ask whether the procedure is

essential for Ms B's care, especially considering her refusal to provide consent. In situations in which it is necessary to perform an emergent life-saving or limb-saving procedure, a decision to treat despite a patient's objections might be justified by the principle of beneficence and by invoking presumed consent. In this situation, lumbar puncture does not guarantee a treatable diagnosis or even a treatment at all. However, it does offer the possibility of a diagnosis (if not of treatment) and could also yield useful prognostic information. For example, though unlikely in this case, lumbar puncture could provide evidence of a treatable indolent inflammatory condition such as autoimmune encephalitis or neurosarcoidosis, which would alter Ms B's treatment plan and overall prognosis. Rubin et al recently proposed a useful guide for making decisions about whether and when to treat, despite objections of alert patients who lack decision-making capacity.<sup>9</sup> Although the guide was developed for patients with surrogates, it might be applicable to unrepresented patients. They advocate consideration of several key questions: "What is the likely severity of harm without intervention?" "How imminent is harm without intervention?" And "what is the patient's reason for refusal?"<sup>9</sup> Addressing these questions would motivate more thorough deliberation about options, particularly when a clinician is deciding whether to intervene despite a patient's objection.

### **Avoiding Unilateral Decision Making**

The need for standardization of decision-making processes for unrepresented patients like Ms B has been magnified, historically, by the risk of these vulnerable patients being overtreated or undertreated.<sup>5</sup> If clinicians were allowed to make unilateral decisions for unrepresented patients, these decisions would probably be made according to inconsistently applied criteria and implemented with substantial variation due to differences in organizational standards or variation in individual physicians' practice patterns, both of which are subject to significant biases.<sup>10</sup>

Hospitals are often undercompensated for care they provide to these patients and thus face financial pressures to limit services, which can diminish the quality of care unrepresented patients receive.<sup>11</sup> One study showed that, within a single hospital, patients with private insurance had lower risk-adjusted mortality rates than those with either Medicare or Medicaid, suggesting variability in care based on payer status even within the same hospital.<sup>12</sup> An unrepresented patient who frequents a given hospital and yet resists treatment might be viewed as a strain on the system, so scrutiny is warranted to ensure decision-making criteria are applied justly, that access to procedures is distributed equitably, and that procedures are implemented with care for each patient.

Similarly to health care organizations, treating physicians must consider how potential biases and conflicts of interest could influence their care of unrepresented patients. Like anyone else, physicians have biases related to any number of factors, including religion,<sup>10</sup>

disability, race, gender, or treatment preferences. For example, physicians' own treatment preferences have been shown to be different from those of [homeless persons](#)—who are likely to be unrepresented—with homeless persons being significantly more likely to prefer full resuscitation practices than physicians.<sup>13</sup>

### **Engaging Input From a Diverse Team**

Ideally, a decision-making process for Ms B and all unrepresented patients would incorporate diverse views from persons who understand the local culture and state laws (such as social workers, attorneys, or members of the clergy) and who are not emotionally invested in the patient's outcome. Additionally, decisions should be made independently of financial stakes or other personal conflicts.<sup>14</sup> Unfortunately, this ideal is often unobtainable in clinical practice. One study showed that 81% of critical decisions for hospitalized patients without a surrogate were made by the treating team alone or in consultation with only one other physician, contravening the above recommendations.<sup>15</sup> Additional oversight only occurred in about 20% of cases, and many of the decisions reached deviated from state law or professional guidelines.<sup>15</sup>

One avenue for securing a temporary or permanent decision maker who meets some of the criteria just discussed is applying for a [court-appointed guardian](#). In many jurisdictions, demand for guardians far exceeds the supply of people willing to serve.<sup>16</sup> In this case, given the chronicity of Ms B's symptoms, her established pattern of frequent hospitalization, and the tempo of decision making (which can occur over weeks, not necessarily hours or days), it might be appropriate to initiate guardianship proceedings. Depending on the jurisdiction, days or months might elapse before a decision maker is authorized. One study reported a median wait time of 37 days from the time of guardianship request to the appointment of a permanent guardian at a public urban hospital.<sup>17</sup>

### **Alternatives to Guardianship**

One innovative strategy if guardianship is not pursued or during the waiting period for an appointment of a guardian is to form a what might be called a *befriending committee* composed of community members who agree to represent the interests of unrepresented patients. In Indianapolis, for example, hospital volunteers were trained to consider and make decisions for unrepresented patients to whom they were assigned.<sup>18</sup> The first cohort of patients represented by befriending committee members experienced an overall decrease in emergency department visits and hospitalizations.<sup>18</sup>

While such programs have shown promising results, they are time and resource intensive. In certain settings, particularly urban safety-net hospitals, the prevalence of unrepresented patients might vastly outpace resources to meet the goals just described. To balance efficiency, neutrality, and due process, input from a multidisciplinary ethics committee is recommended.<sup>19</sup> Many institutions have standing ethics committees

composed of members from diverse professional backgrounds such as physicians, nurses, social workers, ethicists, and lawyers. Ethics consultants are not directly responsible for patients' care but are responsible for helping facilitate deliberation with clinicians and other stakeholders faced with ethically complex decisions. They can help consider what constitutes evidence of patients' preferences—even for unrepresented patients—and are practiced in soliciting a plurality of viewpoints, considering common ground, or motivating consensus in challenging cases. They also can help assess competing obligations and conflicts while prioritizing consistency in applying criteria in making hard decisions. In the case of Ms B and Dr C, an ethics consultation could help fully consider Ms B's objection to the lumbar puncture in relation to the risks of foregoing the recommended procedure. In short, involvement of an ethics consultation service is a way to diversify perspectives at play in decision making, perhaps while guardianship proceedings are under way.

### **Consistency as an Ethical Value in Decision Making**

Ethical issues in Ms B's case include assessing her capacity to make decisions at different points in time, honoring her preferences, and balancing the benefits of respecting her autonomy against the risks of refusing recommended treatment. Dr C and the team can choose from among several approaches to guide decision making about her care, including pursuing a judicially-appointed guardian and enlisting assistance from an ethics committee. Decision makers for unrepresented patients should strive for consistency in treating like cases alike, consider a [patient's interests](#) as fully as possible, and attempt to prevent personal or organizational sources of biases from unjustly influencing decisions.

### **References**

1. American Medical Association. Opinion 2.1.2 Decisions for adult patients who lack capacity. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/ethics/decisions-adult-patients-who-lack-capacity>. Accessed May 9, 2019.
2. 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 [published online ahead of print November 22, 2016]. *J Am Geriatr Soc*.
3. Snyder L; American College of Physicians Ethics, Professionalism, and Human Rights Committee. American College of Physicians Ethics Manual: sixth edition. *Ann Intern Med*. 2012;156(1, pt 2):73-104.
4. 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.
5. Karp N, Wood E. Incapacitated and alone: medical decision-making for the unbefriended elderly. American Bar Association Commission on Law and Aging. [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/200](https://www.americanbar.org/content/dam/aba/administrative/law_aging/200)

[3 Unbefriended Elderly Health Care Decision-Making7-11-03.authcheckdam.pdf](#). Published July 2003. Accessed October 23, 2018.

6. Kopelman LM. The best interests standard for incompetent or incapacitated persons of all ages. *J Law Med Ethics*. 2007;35(1):187-196.
7. Pope TM. Legal fundamentals of surrogate decision making. *Chest*. 2012;141(4):1074-1081.
8. DeMartino E, Doyle C, Dudzinski D, et al. Legal aspects of the physician's role in caring for incapacitated patients: a review of US state statutes. *Am J Respir Crit Care Med*. 2017;195:A7100.
9. Rubin J, Prager KM. Guide to considering nonpsychiatric medical intervention over objection for the patient without decisional capacity. *Mayo Clin Proc*. 2018;93(7):826-829.
10. White DB, Jonsen A, Lo B. Ethical challenge: when clinicians act as surrogates for unrepresented patients. *Am J Crit Care*. 2012;21(3):202-207.
11. Weissman JS, Stern R, Fielding SL, Epstein AM. Delayed access to health care: risk factors, reasons, and consequences. *Ann Intern Med*. 1991;114(4):325-331.
12. Spencer CS, Gaskin DJ, Roberts ET. The quality of care delivered to patients within the same hospital varies by insurance type. *Health Aff (Millwood)*. 2013;32(10):1731-1739.
13. Norris WM, Nielsen EL, Engelberg RA, Curtis JR. Treatment preferences for resuscitation and critical care among homeless persons. *Chest*. 2005;127(6):2180-2187.
14. Meier DE. Voiceless and vulnerable: dementia patients without surrogates in an era of capitation. *J Am Geriatr Soc*. 1997;45(3):375-377.
15. 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.
16. 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*. 2016;65(1):14-15.
17. 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.
18. Bandy R, Sachs GA, Montz K, Inger L, Bandy RW, Torke AM. Wishard Volunteer Advocates Program: an intervention for at-risk, incapacitated, unbefriended adults. *J Am Geriatr Soc*. 2014;62(11):2171-2179.
19. Pope TM. Making medical decisions for patients without surrogates. *N Engl J Med*. 2013;369(21):1976-1978.

**Timothy M. Dempsey, MD, MPH** is a fellow and assistant professor of medicine in the Division of Pulmonary and Critical Care at Mayo Clinic in Rochester, Minnesota. He is the Bioethics Scholar in Training at Mayo Clinic for 2018-2019.

**Erin Sullivan DeMartino, MD** is an assistant professor of medicine and a physician in the Division of Pulmonary and Critical Care Medicine at Mayo Clinic in Rochester, Minnesota. She is a graduate of the clinical medical ethics fellowship at the MacLean Center for Clinical Medical Ethics at the University of Chicago and is on the faculty of the Biomedical Ethics Research Program at Mayo Clinic.

#### **Editor's Note**

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

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