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Ethics of Representing Unrepresented Patients

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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,[1] and another found that 5.5% of ICU deaths occur in unrepresented patients.[2] Moreover, one-third of surveyed physicians who care for critically ill patients admitted to withdrawing life-sustaining treatment in unrepresented patients.[3] 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,[4] 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,"[5] and important medical decisions often must be made during the prolonged process of appointing a guardian.[6] 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.[7] Nevertheless, at one hospital, they made treatment decisions in 77% of ICU cases involving unrepresented patients.[6] Such physician involvement could lead to unwarranted variation in treatment,[8] raising justice-based concerns. Physicians' dual commitment to individual patients and society as a whole[9] 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.[10] 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.[11-13] 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.[14] 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.

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CASE AND COMMENTARY

When There's No One to Whom an Error Can Be Disclosed, How Should an Error Be Handled?

Ryan G. Chiu

Abstract

Disclosure of harmful mistakes to patients and their families can be daunting for physicians, who tend to weigh their ethical obligations to inform against possible underlying fears of retaliation, perceived incompetence, or shame. When a patient is both incompetent and unrepresented, documentation, disclosure, and rectification of errors are particularly important to consider.

Case

An 82-year-old man is brought to the emergency department with altered mental status, fever, and cough after being found on the street. He cannot be identified and is presumed to be homeless. He is admitted to the intensive care unit (ICU) for severe pneumonia with developing acute respiratory distress syndrome, and he requires intubation. After his admission, he has a cardiac arrest. In responding to his cardiac arrest, a communication error transpires.

One nurse, who just spoke with another ICU patient's family, conveys verbally to physicians and others on the team that this patient's family agrees to the team not attempting to resuscitate him. Another physician, Dr K, overhears the nurse's verbal conveyance of this information and assumes (erroneously) that an order not to attempt resuscitation on the 82-year-old patient has just been clarified. So when the 82-year-old patient suffers cardiac arrest, the team does not attempt to resuscitate him. After 5 minutes, Dr K learns that the do-not-attempt-resuscitation (DNAR) message was for a different patient, and though the 82-year-old patient is now hypoxic, Dr K leads the team in successfully resuscitating him.

Shortly thereafter, however, the 82-year-old patient has another cardiac arrest; again, he is revived with cardiopulmonary resuscitation. Dr K is concerned that the patient will have recurrent cardiac arrests secondary to hypoxia. However, nothing is known about his values or preferences, and he continues to have altered mental status. Dr K believes that he has suffered irreversible brain injury from hypoxia during the first delayed resuscitation attempt. Dr K feels that even if the patient were successfully resuscitated following another cardiac arrest, he would have very low quality of life, based on his

knowledge of the literature.[1,2] Dr K thinks that it might now be best to change the 82-year-old patient's code status to DNAR. However, Dr K is concerned that, given the erroneous first DNAR and the patient's unrepresented status, some members of the team might feel compelled to err on the side of providing more aggressive care. Dr K wonders what to do next.

Commentary

Respect for patient autonomy is a core value in medical ethics and forms the cornerstone of the modern patient-physician relationship.[3] At its heart lies the right of patients to make decisions concerning their own medical treatment, even to the detriment of their own health. This principle requires patients to provide informed consent for any treatment or intervention and to be adequately informed when their care does not proceed as planned, due to errors or other factors. Errors are not uncommon—counting among other iatrogenic incidents as the third leading cause of death in the United States[4]—and became an area of increased focus following the release of the Institute of Medicine's renowned report *To Err Is Human: Building a Safer Health System*.[5] It is now a generally accepted ethical duty among US physicians to communicate harmful errors and their implications to the patient and his or her family members.[6,7]

Deontological (duty-based obligation) analysis of error handling is further complicated, however, in situations in which the patient is both incapacitated and unrepresented, as is the case in roughly 8% of hospital ethics consultations nationwide.[2] This essay will propose a 3-part framework for error management pertaining to unrepresented patients. The first part concerns documentation and its role in informing future practice at both the physician and the systemic level. The second part concerns the concept of disclosure—the process of admitting and communicating the mistake in question. Finally, the notion of rectification will be explored, particularly in the context of life prolongation for unrepresented patients.

Documentation

An important purpose of documenting an error is facilitating identification of areas of improvement for both the practitioners directly involved and the hospital system as a whole.[8] It is for this reason that latent errors (less obvious failures of an organization or system that contribute to human errors or to accidents waiting to happen) and "near misses" should be reported to institutions, as they can help institutions identify the cause of an error and respond to its sequelae.[8] One might view Dr K's decision to resuscitate the patient without verifying his identity with the nurse as a lapse in professional judgment. However, it could also be argued that such a lapse could have been prevented by implementing policies or system designs that prevent practitioners from acting without consciously considering relevant information or other systems-level safety measures, such that a single clinician's possible misstep would be less likely to

result in devastating consequences for a patient. Such checks can also illuminate system weaknesses that should be addressed.

In response to an error, clinicians involved should fully document the incident. Clear and complete documentation enables root-cause analyses of causal factors underlying systemic sources of variation in clinical practice.[9] Hospital policies can be tailored to address these factors in order to prevent similar errors in the future.

Disclosure

In contrast to documentation, a process largely independent of patient or surrogate involvement, error disclosure can be complicated by a lack of persons to whom the physician could otherwise express contrition and sympathy. During a disclosure process, a physician could inform the patient or—if he or she lacks decision-making capacity—an available surrogate that an error occurred, offer a sincere apology on behalf of everyone involved, and outline next steps for rectification. Before addressing whom to tell in this case, it is important to consider the value of error disclosure. First, error disclosure serves to preserve trust between patients and their physicians.[10] Second, it serves a risk management purpose for both physicians and hospital systems,[10] as ineffective communication is a risk factor for malpractice claims.[11] Conversely, disclosure of an error renders a practitioner less likely to be named as a defendant in a lawsuit and is consequently associated with lower malpractice costs.[12]

For unrepresented patients, of course, those who could seek financial retribution or demand an explanation are absent. Nevertheless, finding someone to whom to disclose the error could be helpful, if not therapeutic, for the clinician directly involved, as it involves the clinician setting aside his or her pride in order to reflect on what just transpired.[13] Disclosure could enable Dr K to mentally organize events leading up to the incident in a manner that is coherent and permits identification of strategies for preventing errors. If Dr K were a trainee, an attending physician overseeing the patient's care would be a suitable person to whom to disclose the error. A senior colleague would, presumably, be able to offer support and constructive feedback, such that Dr K might be able to feel that the best has been made of a bad outcome, that an act of ownership and contrition has been rendered, and that learning can be ongoing.

Rectifying an Error

What constitutes adequate rectification of an error can be an ongoing source of ethical and clinical consideration, but, for purposes of discussion here, rectification can be construed as a restorative process related to either a harmed patient (by minimizing his or her discomfort) or, in the case of a patient's death, memories of that patient. Unfortunately, some errors could render a patient unresponsive or unable to clarify his or her end-of-life wishes.

In the United States, prolongation of life is generally regarded as an appropriate default for an incapacitated patient who has not indicated otherwise through an advance directive, prior communication, or a surrogate decision maker.[14] But prolonging life is only ethically acceptable when benefits of prolonging meaningful life outweigh harms of delaying death.[15] Therapeutic futility, for example, is commonly invoked to justify withdrawal of life supporting treatments when, according to a Society of Critical Care Medicine policy statement, continuing treatments "will not accomplish their intended goal … i.e., treatments … have no beneficial physiologic effect."[16] Defining what constitutes therapeutic futility requires input from a physician not involved in the patient's care who can inform considerations of what might be regarded as physiologically beneficial.

Dr K has a number of resources available to him. He should consider seeking advice from physicians not directly involved in the unrepresented patient's care who have expertise in critical care and palliative care. In addition, hospitals typically have an ethics committee whose main purpose is to adjudicate ethically difficult cases in patient care[17]; ethics committee members as well as interdepartmental colleagues could help him assess therapeutic futility. While some might argue that the initial mistaken DNAR order should not be treated as a *fait accompli* and that more aggressive measures are warranted to remedy it, prolongation of life could result in additional harm being suffered by the patient.

Conclusion

In cases in which an error is made in the care of an unrepresented patient, the absence of a surrogate does not preclude the clinician's ethical responsibilities to document, disclose, and, insofar as possible, rectify the mistake. As suggested here, the obligations of physicians and their organizations to an unrepresented patient are not all that different from those owed to other patients.

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This essay is the winning essay of the 2018 John Conley Ethics Essay Contest. The case to which this commentary is a response was developed by the editorial staff.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

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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,[1] the American Geriatrics Society recommends that a patient's treatment team should make such decisions,[2] and the American College of Physicians posits that a court-appointed guardian should always be utilized.[3] 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.[4] 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,[5] 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.[6,7] 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.[5] For example, in some states, treating clinicians assume authority to make decisions for their unrepresented patients, but other states expressly forbid this practice.[8]

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.[9] 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?"[9] 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.[5] 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.[10]

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.[11] 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.[12] 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,[10]

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.[13]

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.[14] 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.[15] Additional oversight only occurred in about 20% of cases, and many of the decisions reached deviated from state law or professional guidelines.[15]

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.[16] 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.[17]

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.[18] The first cohort of patients represented by befriending committee members experienced an overall decrease in emergency department visits and hospitalizations.[18]

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.[19] 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.

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CASE AND COMMENTARY

Should Aggregate Patient Preference Data Be Used to Make Decisions on Behalf of Unrepresented Patients?

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Abstract

Patient preference predictors aim to solve the moral problem of making treatment decisions on behalf of incapacitated patients. This commentary on a case of an unrepresented patient at the end of life considers 3 related problems of such predictors: the problem of restricting the scope of inputs to the models (the "scope" problem), the problem of weighing inputs against one another (the "weight" problem), and the problem of multiple reasonable solutions to the scope and weight problems (the "multiple reasonable models" problem). Each of these problems poses challenges to reliably implementing patient preference predictors in important, high-stakes health care decision making. This commentary also suggests a way forward.

Case

Mr T is an 88-year-old black man with squamous cell carcinoma of the throat metastatic to the brain, complicated by recurrent seizures. The patient is admitted from his medical care facility because he is no longer able to swallow due to tumor progression, and there is concern for pending airway occlusion. Mr T's wife passed away many years ago and he has no children, other family, or friends. Mr T has had altered mental status, likely due to the brain metastases and recurrent seizures. He is unable to speak and intermittently makes uninterpretable vocalizations. The oncology team is not offering to continue Mr T's treatment and has predicted that he will likely die within weeks without interventions, such as a percutaneous endoscopic gastrostomy (PEG) tube and tracheostomy, and in less than 6 months in any case.

In a multidisciplinary meeting, Dr J references an article featuring a predictive model that shows that being black is consistently associated with preferring more end-of-life treatment in medical settings.[1,2] Dr J asks, "Should we conclude from this article that Mr T would want a PEG tube and tracheostomy?" Dr O, an oncologist, voices doubt about applying population-level data to decisions involving particular patients. Dr J says, "Yes, I wondered about that, too." He then mentions a study showing that 78.9% of patients would prefer to have aggregate data incorporated into processes of making clinical decisions on their own behalf.[3] They further discuss and wonder what to do.

Commentary

Care for incapacitated patients generates familiar moral problems. Foremost among these is the problem of making treatment decisions on their behalf. The cause of the problem is obvious. Typically, medical professionals defer to a patient's (informed) decisions, but an incapacitated patient clearly can't make the relevant treatment decisions. What to do? The obvious thing to do is for medical professionals to defer to some other source with the moral standing to speak on behalf of the incapacitated patient.

Traditionally, the sources thought to have the moral standing to direct treatment on behalf of incapacitated patients are of 2 broad sorts: advance directives and surrogates. In an advance directive, a patient expresses her preferences over a range of treatment decisions in advance of her incapacitation. It's obvious why advance directives plausibly have the relevant sort of moral standing: deferring to a patient's advance directive is a way of deferring to that patient's own decisions at one remove, as it were.[4-7] In surrogate decision making, third parties make treatment decisions on behalf of the incapacitated patient. These surrogates are supposed to have the relevant moral standing either because of a formal relationship—say, medical power of attorney—or because of a more informal relationship that intuitively justifies such moral standing—say, in the absence of medical power of attorney, the surrogate's being a spouse or an adult child. (Of course, the two often go together, as relatives make natural candidates for power of attorney.)[8,9]

Recently, a third source of moral standing for making treatment decisions on behalf of incapacitated patients has been proposed: so-called patient preference predictors (henceforth, PPPs).[1,10,11] Very briefly, PPPs are statistical models that predict the treatment preferences of a patient described by a combination of known demographic variables—such as age, educational level, religion, and so on—based on aggregate data about the treatment preferences of persons with demographic profiles similar to the patient.[12-14] Before turning to the moral standing of PPPs, let me mention one issue in order to set it firmly aside in what follows. One immediate reaction to the suggestion that we predict an incapacitated patient's preferences using patient demographic descriptors that are likely to be known—especially, race, gender, and age—is that it's radically unclear how robust such predictions might be. The first thing to say in response is that there are in fact some broad, relatively strong correlations between such factors and, for instance, preferences for palliative care at the end of life.[15] Now, it's true that we lack the kind of broad-based statistical data over a range of treatment options that would be necessary to make PPPs widely useful in a clinical context. But it's trivial to imagine how we might go about acquiring such data. For instance, Rid and Wendler propose a national PPP survey of competent adults that could be used to correlate the most likely relevant demographic descriptors with patients' preferences over a wide range of treatment options in a wide range of scenarios.[1] There are other possibilities,

too. In any case, this practicability question isn't one that I'll be concerned with in what follows.

So, why think PPPs have any moral standing to determine treatment decisions on behalf of patients? The intuitive argument is straightforward. Recall that the best-case scenario is one in which a patient's treatment reflects her own informed decisions. Advance directives and surrogates are ways of trying to epistemically access—in more or less direct ways—what we think those informed decisions would have been. Moreover, that they are directed toward the patient's own preferences is what explains why they have the kind of moral standing they do in the process of making treatment decisions on behalf of incapacitated patients. Likewise, the use of PPPs is a way of trying to epistemically access an incapacitated patient's own preferences with respect to her treatment. Intuitively, then, if advance directives and surrogates enjoy the relevant sort of standing, then PPPs ought to enjoy that same standing.

In any case, I'm going to assume we're sometimes justified in using PPPs to make treatment decisions on behalf of incapacitated patients. This assumption is compatible with restrictions on their permissible use—perhaps we think they can only be used to supplement surrogate decision making or that they can only be used in the absence of both an advance directive and a suitable surrogate.[12] These restrictions won't concern me here. Instead, my interest is more narrowly focused on conceptual challenges to reliably implementing patient preference predictors in such high-stakes health care decision making.

Suppose we are justified in sometimes using PPPs; there are 2 interesting problems that arise in the context of using PPPs that don't arise for advance directives or surrogates. (There are, of course, other problems. For instance, Rid and Wendler[1]—2 proponents of the use of PPPs—point to the danger of stereotyping inherent in this sort of statistical model using readily apparent demographic descriptors. In other work,[12] I've also argued that PPPs face a closely related problem—analogous to a familiar problem in legal scholarship—having to do with moving from bare statistical evidence to normative conclusions. These problems, while important, won't concern me here.) I'll argue that the presence of these 2 interesting problems generates a third, quite serious difficulty for the use of PPPs in a clinical setting. I'll then close by briefly explaining one strategy for solving this third difficulty as a way of laying out a fruitful direction for future research. But first, I discuss the 2 initial problems.

Two Initial Problems With PPPs

The scope problem. Recall that a PPP can usefully be thought of as a function that takes as input known characteristics of the patient and produces a probabilistic prediction regarding the patient's preference for (or against) a particular medical intervention based on aggregate data from people who share similar characteristics with the patient. Not all

known information about a patient ought to be used in producing these probabilistic predictions. In particular, we ought to exclude uncontroversially false (but suitably important) normative beliefs that might be correlated with patients' preferences, and we ought to exclude some (but not all) normatively irrelevant characteristics of patients that might be correlated with patients' preferences. Hence the *scope problem*. The scope problem is the problem of restricting, in a principled way, what sort of information can be used as inputs to a PPP. Let me comment briefly on false normative beliefs and irrelevant characteristics as a way of making intuitive the case that these inputs ought to be excluded from PPPs.

Take false normative beliefs first. Suppose we knew that victims of long-term domestic abuse were much less likely to prefer palliative care in particular circumstances. Suppose further that we had a normative explanation of this fact, viz, that victims of domestic abuse have a diminished sense of their own worth as compared to the worth of others—they (incorrectly) believe that they somehow "deserve" suffering or that their suffering somehow counts for less. I take it for granted that we would want to exclude such a false belief from our PPP when using it to deliver a verdict regarding a patient's preferences in treatment. The argument for this claim is straightforward; spelling it out in detail would require too much space in the present context. Roughly, you can't derive a correct normative verdict regarding how you ought to treat a patient, ie, what medical treatment to provide to her, from that patient's preference grounded in a manifestly false normative belief, ie, that her suffering is less morally important than others'.

Now take normatively irrelevant facts about patients. We know that religion is strongly correlated with preferences regarding end-of-life care.[16] And religious identity is precisely the kind of thing we intuitively want to include as input to a PPP. So far, so good. But now notice that there's nothing that rules out the possibility that (say) whether one prefers the NFL to the NBA correlates quite strongly with one's preferences regarding end-of-life care. One response would be to simply include that sports preference among the demographic descriptors that, if known, could be used by a PPP to predict a patient's preferences over the relevant treatment options. But this is strongly counterintuitive. While there doesn't appear to be any—or, at least, much—intuitive resistance to taking religion as a relevant input to a model designed to predict what an incapacitated patient would want, there is a strong intuitive case against taking sportsball preference into account in the same way. Again, spelling out the details of this argument would require too much space in the present context, but here, roughly, is the idea. Some facts about one's self are more or less central to one's identity. And when it comes to making life-altering—and potentially life-ending—decisions, it's perfectly natural to want those decisions to be made on the basis of those facts about one's self that are central—for most people, their religious identity—rather than on the basis of those facts that float around the periphery—again, for most people, their preferring the NBA to the NFL, or vice versa.

Hence, the scope problem is this: How should we restrict, in a principled way, the sort of information that can be appropriately used as the input to a PPP? (If you're not particularly bothered by this problem because you think it's obvious that all information ought to be allowed as input to a PPP, the scope problem still generates the problem that below I call the multiple models problem.)

The weight problem. The second problem is what I'll call the *weight problem*. The weight problem is the problem of explaining, in a principled way, how to correctly weight the information that serves as input to a PPP. Even if we have a solution to the scope problem in hand, this solution does not tell us how to weight the various inputs to a PPP in coming to a final verdict. For instance, while we might agree that (say) someone's ethnicity ought to serve as input to a PPP, you might think that predictions based on ethnicity ought to be weighted less as compared to (say) predictions based on religion, and I might think the opposite. This disagreement over the correct weight assignment for these 2 factors could obviously lead to disagreement over the correct treatment decision. (And assuming there's some fact of the matter about how we ought in fact to treat the patient, it can lead predictably to patient harm.)

One natural response to this problem is to posit that there is some objective principle for weighting the inputs to the PPP that assigns some specific weight to each—0.3 to ethnicity, 0.6 to religion, say. But it's hard to see what the principled way of determining the values of such an objective weighting might be. (This is what I meant, above, in saying that the problem was one of explaining in a principled way how to weight the various inputs to a PPP.) The difficulty arises because it's hard to imagine what sort of data we could acquire—either by sampling existing data or by gathering new data—that would lead us to reasonably conclude that always, everywhere, for patients who are (say) both Asian and Catholic, their ethnicity ought to be weighted (say) ⅓ as much as their religion. This is not to say that we might not gain some information that would lead us to a range of likely values for these relative weights. But then we face the multiple models problem, which I'll turn to now.

Multiple reasonable models problem. In order for the use of PPPs in a clinical context to be morally permissible, the scope and the weight problems require solutions; as yet, they have none. But things are even more complicated than this. For, together with some commonsense observations about the difficulty of the issues involved, these problems generate what I'll call the *multiple reasonable models problem*. The multiple reasonable models problem is this: there will be reasonable disagreement over how to solve the scope and the weight problems.

A very quick word about *reasonable* disagreement. To say that these disagreements are reasonable is to say that well-informed persons reasoning together in good faith over what information should be included in our PPPs (the scope problem) and how to weight

that information (the weight problem) could in principle continue to disagree and that neither need be making a normative or nonnormative mistake correctable by further analysis of the values at stake or the data available.[15] Such reasonable disagreement is presumably due to what John Rawls calls, in a related context, the very difficult "burdens of judgment" when it comes to normative questions.[17] The sort of reasonable disagreement I have in mind is analogous to (indeed, might be a species of) Rawls's idea of reasonable disagreement in a liberal political society over what comprehensive doctrine is correct. In the present context, the claim is not that the presence of reasonable disagreement informs the correct political arrangement; instead, it is simply that in virtue of reasonable people's reasonable disagreement over the correct "comprehensive doctrine," there will be downstream reasonable disagreement over how to solve the scope and weight problems, ie, disagreement over what factors ought to be used in predicting agents' preferences and how to weight those factors. This is not to say that all such disagreement over how to solve these problems would be reasonable. This is just to say that some such disagreement would be.

But, then, given that some such disagreement is reasonable, in clinical contexts medical professionals will be forced to decide between equally reasonable PPPs that deliver equally reasonable but incompatible verdicts regarding patients' preferences, ie, each PPP is an equally reasonable function that takes us from known information about a patient to (competing) verdicts regarding her preferences for medical treatments. Hence, the multiple reasonable models problem arises.

We can see that the scope problem allows for reasonable disagreement by focusing on either of the 2 illustrations of it I offered above: the case of false normative beliefs and the case of normatively irrelevant facts about patients. I offered what I took to be uncontroversial instances of the sorts of things we want to exclude from our PPP: on the one hand, the correlation between patients' normatively false belief that they don't merit care (because of being victims of domestic abuse) and their care preferences, and, on the other hand, the correlation between patients' normatively irrelevant preference for the NBA over the NFL and their care preferences. But it should be obvious that there can be reasonable disagreement of the sort just described over both these types of cases. For instance, you and I might reasonably disagree over whether some patient's normative belief is actually false or not; or we might disagree over whether this or that characteristic is suitably central to patient identity to merit inclusion in the PPP.

To see that the weight problem allows for reasonable disagreement, notice that even if we agree on whether to allow both ethnic and religious identity to inform our PPP, we might reasonably disagree over how to weight those factors. Returning to the discussion above, you might think we ought to assign ethnicity a weight ⅓ that of religion in the present context; I might disagree. This disagreement would not be unreasonable;

instead, it would presumably be due to what is itself reasonable disagreement on how to value religious as compared to ethnic identity.

The multiple models problem is hence where the scope and the weight problems truly earn their keep: what these observations show is that, even assuming we've provided *some solution or other* to the scope and weight problems, this solution will just be one among several reasonable alternative solutions. Hence medical professionals will still face reasonable disagreement over *what PPP to use*; in a clinical context, this is a real barrier to the use of PPPs in making treatment decisions on behalf of incapacitated patients.

Prospects for Solving the Multiple Reasonable Models Problem

Let me close with a couple of quick remarks on how I think we should move forward. We can begin by noticing that there appears to be an analog of the multiple reasonable models problem when it comes to the use of surrogates. This is clearest in the absence of a patient's formal designation of a surrogate: in that case, it's possible for reasonable people to reasonably disagree over who should serve as the patient's surrogate. For instance, we might reasonably disagree over whether it should be (say) the patient's relatively new spouse or her adult child. When this happens, we appear to have a way to resolve the disagreement or at least to move forward. Assuming the patient resides in a state that does not specify an order in which relatives should be identified as surrogates, we can split the decision making between the surrogates and encourage them to decide together.

What might the analog of this solution look like in the case of PPPs? My suggestion, which for reasons of space I can only gesture to here, is straightforward: we should give equal weight to competing PPPs that are reasonable in the way identified above. Two PPPs will count as competitors in any given case when they deliver differing probabilistic judgments regarding a particular patient's preferences over the available treatment options.[18,19] Two comments are in order. First, what this means in practice is that we shall need to weigh the verdicts of competing PPPs by updating our prior credences about a patient's preferences in the ordinary way by, for instance, conditionalizing on those competing verdicts as independent pieces of evidence. Second, the ethical benefit to patients of this approach should be clear. For notice that the trouble here is caused by the fact that there's reasonable disagreement over which PPP—which way of solving the scope and weight problems—might be correct. But if that disagreement really is reasonable, then our practice ought to reflect the underlying normative uncertainty, and patients deserve treatment that does so. After all, patients might themselves reasonably have one or the other view of the matter. So an approach that instead simply plumped for one or the other PPP that delivered incompatible verdicts regarding a particular patient's preferences on a particular occasion appears viciously arbitrary—not just from the theoretical point of view, but also from the point of view of patients themselves.

Of course, there is much more to say about the merits of (and problems with) this approach. And we shall still need some account of which ways of solving the scope and the weight problems count as reasonable as opposed to unreasonable (and so are taken into account in the way just suggested). That is a profitable direction for future theoretical research on the use of PPPs in clinical contexts.

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CASE AND COMMENTARY

Should Dialysis Be Stopped for an Unrepresented Patient With Metastatic Cancer?

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Abstract

Unrepresented patients (also referred to as unbefriended, patients alone, patients without proxy, or isolated patients) are among the most vulnerable persons entering the health care system. Legislation concerning these patients varies across the United States, resulting in disparities in care. For example, the statutory definition of who is unrepresented varies. In some states, clergy or close friends may act as surrogates; in other states, they cannot do so. Available end-of-life options also differ, creating significant disparities in end-of-life care for these patients.

Case

Mr B, a 74-year-old man with a prior history of hypertension and mild dementia, was admitted to the hospital from his nursing home after experiencing swollen limbs, shortness of breath, and altered mental status. In the emergency department, due to hyperkalemia and acute renal failure, Mr B was emergently dialyzed and stabilized. Mr B was minimally communicative, unable to provide his own health history. The team admitted Mr B, obtained his records, and learned that Mr B was diagnosed with renal cell carcinoma one year ago and received a total left nephrectomy. One week following his admission, Mr B's mental status deteriorated. He continued dialysis, as his renal function showed no signs of improvement; a CT scan revealed brain metastases; and consultation with oncology confirmed no curative options were available to him.

Mr B remained unable to contribute to his treatment plan. He has no known relatives and has received no calls or visitors. Dani, a nurse caring for Mr B, shared that, following his nephrectomy, Mr B's dementia symptoms worsened and his memory and attention were poor. Dani also relayed that Mr B refused to complete his part of the medical orders for life-sustaining treatment form when he first entered a nursing home 5 years ago. Dani could not say what Mr B would choose today but shared that when Mr B was diagnosed with renal cancer, he said, "I'm going to fight this cancer so hard."

Dr A, Mr B's primary attending physician, who is committed to keeping Mr B comfortable and allowing him a natural death, suggests that Mr B's dialysis be stopped. Dani wonders

whether stopping dialysis would express disregard for Mr B's wishes. The team wonders how to proceed.

Commentary

Patients who lack the capacity to make medical decisions for themselves, have no advance directive, and have no one to speak on their behalf are known by several names—unrepresented, unbefriended, patients alone, or patients without proxy. In hospitals across the country, there are thousands of patients like Mr B who often face major medical decisions without the decisional capacity to navigate them and without a loved one to take the helm.[1] While some unrepresented patients without decisional capacity still retain the ability to articulate their preferences and share their values, many, like Mr B, cannot. Without an advocate at their bedside, they face increased risk of being overtreated or undertreated as well as receiving treatment that is inconsistent with their preferences.[2]

With neither an advance directive nor a surrogate decision maker to guide them—and often without any guidance from the patient—clinicians must make medical decisions without knowing how those decisions might align with the patient's values. Clinicians like Dr A face the challenging task of crafting a treatment plan, often with life-or-death consequences. The less a clinical team knows about who a patient is or what the patient's preferences might be, the harder it becomes to know how to "do right" by that patient.

States have taken very different approaches in drafting laws concerning decision making for the unrepresented, with some states granting complete authority to treating clinicians and others providing no mechanism for decision making whatsoever.[1,3] Therefore, the end of Mr B's life could look very different depending on where he was admitted. Significant attention has been given to how the variability in state laws guiding decision making for unrepresented patients impacts timeliness of care, quality of care, and medical options available to this population.[1,2,4] End-of-life options available to the unrepresented also differ, creating significant disparities. For example, hospice enrollment is not available by statute to the unrepresented in every state.[5] Treatment of unrepresented patients within states can also vary due to hospital policy and practice.[6,7]

The variability in available treatment options affects the ethicality and process of decision making as much as the final decision itself. It is through decision-making processes that promote careful deliberation that we are best able to honor the patient, even when the outcome might be the same whichever law is followed. New York and North Carolina are 2 examples of states with disparate approaches to end-of-life care options for the unrepresented. We will use these extreme cases to examine the ethical and clinical impact of state statutes on clinical practice and health care outcomes for patients such as Mr B.

North Carolina

North Carolina and Oregon are the only 2 states that, by statute, allow attending physicians to unilaterally terminate life-sustaining treatment under specific conditions.[8,9] In North Carolina, if Dr A determined to a "high degree of medical certainty" that Mr B would remain incapacitated and she, along with a second concurring attending physician, reached the conclusion that Mr B had "an incurable or irreversible condition that [would] result in … death within a relatively short period of time,"[8] Dr A would be free to withhold or discontinue life sustaining treatment (LST). In Mr B's case, this would mean she could unilaterally stop his dialysis. North Carolina does permit "an individual who has an established relationship with the patient, who is acting in good faith on behalf of the patient, and who can reliably convey the patient's wishes" to act as a surrogate.[8] However, there is no statutory guidance regarding what constitutes an "established relationship" or what might count as knowledge of the patient's wishes, adding yet another level of subjectivity to this process. Some hospitals in North Carolina thus might determine that the nurse, Dani—if willing—has sufficient information about Mr B to serve as decision maker, and some might feel that his casual relationship with and limited knowledge of Mr B do not qualify him.[10]

Granting Dr A this decision-making power, while potentially efficient, is problematic. Other than Dr A's consulting with a second attending physician regarding Mr B's clinical status, there is no requirement that Dr A confer with any other clinician, interdisciplinary team, or ethics committee when deciding to terminate dialysis. She would not have to account for how she reached her decision, and any conflicts of interest or inherent biases about quality of life could go unchecked.[11] Dr A would not have to consider what Mr B's values might have been when weighing the risks and benefits of terminating dialysis.

Although Mr B's specific preferences are unknown, there is some information available, such as his statement about wanting to fight cancer. In order to honor Mr B, this information must be at least considered when making current medical decisions. A single physician might take the time to consider insights into unrepresented patients' values when deliberating, but there is no guarantee that he or she will do so. Even if a clinician were to take the time, weighing risks and benefits of particular interventions in the light of a patient's prognosis and values is a delicate process that becomes even more complicated when the information we have about a patient is scant. The risk of overvaluing or undervaluing information can be mitigated through a more deliberative process involving perspectives of an interdisciplinary team. This approach can also decrease the chances that Mr B would receive different treatments depending on the attending physician on service.[11]

The decision-making model used by Dr A not only lacks transparency, has potential for bias, and does not specify a process, but also places an unfair burden on the shoulders of the attending physician. Even though Dr A believes that allowing Mr B a natural death is

in Mr B's best interest, making that decision for him or a similar patient can take a toll on her. Deciding for others is a significant burden and can produce distress and burnout,[12] although these effects can be mitigated when decision making is done in conjunction with other health care professionals or using a team model. There is evidence that this approach—wherein clinicians unilaterally decide on the withholding or withdrawing of LST—is widely used though only authorized explicitly by North Carolina and Oregon.[6]

New York

If Mr B were receiving his care in New York State, Dr A would not have the authority to unilaterally stop dialysis. The New York Family Health Care Decisions Act states that LST can only be withdrawn if the treating attending physician and an independent physician agree that the treatment—in Mr B's case, dialysis—would offer "no medical benefit" because the patient would "die imminently, even if the treatment is provided" and that the treatment "would violate accepted medical standards."[13] With the nephrologist open to continuing dialysis, it would be challenging to argue that dialysis violated acceptable medical standards.

In 2015, New York State law was amended to provide hospice care as an option to patients like Mr B with the approval of a hospital ethics review committee (ERC).[13] An ERC—composed of at least 5 people including an attending physician, a registered nurse, a community member, and 2 others, one of whom must be a health care professional—is tasked with reviewing the hospice recommendation and must give its approval before a patient can be enrolled. Prior to 2015, Dr A would have had little room to do anything other than maintain Mr B on what she viewed as unduly burdensome dialysis, keep him comfortable, and await his death. Now Mr B could be transferred to hospice care, and his dialysis could be discontinued with approval of an ERC. The criteria for withdrawing LST for the purpose of hospice enrollment allows for withdrawal in situations in which the treatment would be an extraordinary burden to the patient and provided that the patient has an illness or injury that could be expected to cause death within 6 months, whether or not treatment is provided.[13] Members of the ERC would have the opportunity to hear from Dr A, the nephrologist, the bedside nurse, and any other clinician engaged in Mr B's care. The ERC would then weigh the benefits and burdens and would need to reach consensus regarding whether hospice would be in Mr B's best interest.

An ERC does not guarantee that Mr B's values will be unearthed and honored, but it provides a space for stakeholders with different perspectives to come together, share what they know about Mr B, and try to decide whether hospice enrollment and potential withdrawal of LST for that purpose is in his best interest. As the person with the greatest knowledge of Mr B, Dani would also be welcomed to share insights.

A Different Fate From State to State

In North Carolina, Mr B might no longer be receiving dialysis. In New York State, Mr B might be in hospice care. In states where the law is silent, he might still be in the hospital receiving dialysis, or the hospital might be engaged in the often-unwieldy process of seeking guardianship for him.[14] Regardless of whether dialysis is terminated, Mr B will likely die in the next few days to months. However, the process by which his treatment options are decided upon is as important as the outcome itself. It is both a profound privilege and a profound responsibility to be the de facto advocate for a patient's best interest. A statute that demands a deliberative, interdisciplinary process is more likely to honor the patient.

In a society that prizes autonomy, making decisions—especially end-of-life decisions—for those who have no voice is inherently a fraught process. Several states have developed legislation to address this problem, but there is no perfect system for making end-of-life decisions for unrepresented patients. Every unrepresented patient deserves an individualized assessment of his or her needs, taking into consideration not only medical facts but also his or her values and wishes. This task can feel impossible when so little is known about who the patient is and what he or she values. The most effective means of ensuring that patients like Mr B receive care consistent with their values is by preventing them from becoming unrepresented patients.[1] While these patients often come from growing marginalized populations such as the homeless and elderly, we should not automatically assume that they are without connections.[15] Clinicians should proactively identify patients at risk for becoming unrepresented and support them in identifying potential surrogates and documenting their wishes. When Mr B was first hospitalized for renal cancer, his oncologist might have asked him: "Whom do you trust?" "Who knows you best?" No statute can replace the astute clinician's ability to care for the whole patient.

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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.

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HEALTH LAW

Who Makes Decisions for Incapacitated Patients Who Have No Surrogate or Advance Directive?

Scott J. Schweikart, JD, MBE

Abstract

Unrepresented patients are those who have no surrogate or advance directive to guide medical decision making for them when they become incapacitated. While there is no perfect solution to the problem of making medical decisions for such vulnerable patients, 3 different approaches are noted in the literature: a physician approach, an ethics committee approach, and a guardianship approach. Recent policies and laws have required an approach that is "tiered" with respect to both who is involved and the gravity of the medical treatment questions at issue. In a general sense, some variant of a tiered approach is likely the best possible solution for jurisdictions and health institutions—both those already with and those without a tiered approach—to the challenging puzzle of treating unrepresented patients.

Single Greatest Category of Problems

Unrepresented patients are incapacitated individuals whom Pope describes as having "no available friends or family to make medical decisions as 'default' surrogates."[1] These patients typically fall into 3 groups: those who are homeless or mentally ill, those who by "choice or life history" do not have family or friends who could act as a surrogate, and those elderly patients who have outlived their family and friends.[2] Indeed, the problem of addressing the "care of decisionally incapable patients" who have no surrogate to engage in the decision-making process is a bioethical puzzle and has been deemed by Karp and Wood to be "the single greatest category of problems" encountered by hospitals and clinicians.[3]

The United States currently faces a significant problem with regard to decision making for unrepresented patients. As recently as 2017, there were more than 70 000 unrepresented patients in the United States.[1,4] However, some estimates suggest that the number may be well over 100 000[1,5] and possibly as high 330 000.[6] The number of unrepresented patients, already substantial, is forecasted to increase. Volpe and Steinman note, "Between 2010 and 2030, the size of this group [unrepresented patients] is expected to rise dramatically due to the aging Baby Boomer generation, the expanding population of elderly with dementia, and the growing number of seniors who

live on their own."[5] Physicians frequently encounter these patients, especially in the critical care setting where determinations of withdrawing life support are at their most acute. Indeed, one study found that physicians reported considering withholding or withdrawing life support from 37% of unrepresented patients in an intensive care unit in which 16% of patients admitted were unrepresented.[7] In another study, 5.5% of patients who died in ICUs were unrepresented.[8]

Approaches to Making Decisions

Generally, there is agreement that "a substituted judgement or a best interest standard" is best to help guide decision making for unrepresented patients,[9] although laws and policies vary in how best to uphold a best interest standard.[4,9] As the Hastings Center notes, "[t]here is as yet no consensus on the proper solution."[10] However, state laws and institutional policies attempt to solve the problem largely through 3 different approaches regarding the choice of decision maker: physician, ethics committee, and guardianship.[5] Each of these approaches—applicable to the care of unrepresented patients generally and in specific situations such as end-of-life care—has certain advantages and disadvantages, underscoring that no one approach alone provides a solution.

Physician approach. The model of allowing the physician to be the ultimate decision maker is the main approach, with White et al's study demonstrating that 81% of life support decisions for unrepresented patients were made "by the intensive care unit team alone or … [with] another attending physician."[8] Some states allow physicians to act as decision makers until a guardian can be appointed.[11] However, it is interesting to note that 39 states do have laws that prohibit—explicitly, implicitly, or possibly—physicians from acting as a general surrogate.[10] These laws prohibit physicians from becoming general surrogates in the sense that they cannot be designated or appointed a surrogate for their own patient—even for patients who have decision-making capacity and may wish to actively choose their physician as their surrogate should the need arise. As Rosoff notes, most of these laws seem to be motivated by concerns about "the possibility of a financial conflict of interest on the part of the physician."[11] Nevertheless, it is interesting to note that physicians can be the sole decision maker for unrepresented patients. Some states directly empower physicians to make decisions for unrepresented patients, like North Carolina, which will allow physicians to make end-of-life decisions for unrepresented patients without court approval as long as reasonable efforts are made to find a surrogate.[11,12] Arguably, this law stands partly in contradiction to North Carolina's statute that bars physicians from being a "health care agent" to their patient (though why lawmakers allowed such a contradiction is unclear).[11,13]

Ethics committee approach. Hospital ethics committees help make decisions for unrepresented patients by deliberating and then offering a recommendation. Many hospitals consult an ethics committee of their own accord; some states have laws that mandate an ethics committee's involvement; and other states' laws only prefer

committee involvement but do not mandate it.[1] The *AMA Code of Medical Ethics* stipulates that physicians have an "ethical responsibility" to consult an ethics committee when making decisions for those patients who lack capacity and are without an available surrogate.[14] The advantage of an ethics committee is that it can, as Pope notes, "offer various perspectives and can utilize a multifaceted array of both medical and ethical considerations," in contrast to a singular decision maker, such as a physician or guardian, who may be subject to financial incentives or bias.[1]

Guardianship approach. When a court determines that an individual lacks capacity to make decisions, it appoints a guardian with legal authority to make decisions for that person.[1] Court appointment of a guardian to make decisions on behalf of an unrepresented patient might seem like a simple solution on its face, but it is generally disfavored and considered an inadequate solution.[1] Karp and Wood note that guardianship is criticized for being "too costly, too time consuming, [and] overly cumbersome."[3] Additionally, it has been criticized because guardians often are not adequately trained and do not know the patient.[1] Public guardianship (ie, guardianship created by court appointment of a person or agency unknown to the patient) may have value as the "ultimate safety net" for patients, but programs need adequate funding and staff, something that is not a reality in all states.[3] The concern about adequacy of funding is echoed by Moye et al, who note that "if the public guardianship system is not adequately structured or funded, healthcare providers and hospital ethics committees are likely to be involved certainly before and sometimes after guardianship appointment."[15]

Despite criticism, benefits of guardianships exist. Karp and Wood argue that public guardianship is an important option for unrepresented patients, especially those with prolonged medical issues, and note that "public guardianship should be readily available for those in need, particularly when the decision making may be ongoing."[3]

Discussion

There is a significant debate in the literature about which decision-maker approach is best for unrepresented patients (both in the general sense and in more specific situations such as end-of-life care), with commentators falling into 2 basic camps: one that supports physicians and one that supports ethics committees. While there is support for guardians, the literature suggests a more prominent debate about whether physicians or ethics committees should serve as decision makers. These 2 schools of thought are illustrated in the divide between Pope (a strong advocate of ethics committees as decision makers) and Courtwright (a strong advocate of physicians as decision makers).[1,2] Pope encapsulates this divide well, noting that it stems from 2 "fundamental questions": "(1) whether the dominant 'solo' physician model is acceptable and, (2) if not, 'how much' of a second opinion [i.e. an ethics committee] is required."[16]

Pope strongly argues that physicians alone should not be making treatment decisions for unrepresented patients. He explains that "when physicians don't need to explain their treatment decisions to another decision maker, the bases for those decisions are less clearly articulated and more susceptible to the physician's idiosyncratic treatment style."[17] Also problematic, as noted earlier, is that physicians have conflicting interests and obligations that may influence their decisions as surrogates. For example, as White et al note, physicians are perceived to have "ethical commitments to individual patients and to society at large to manage resources in a cost-conscious manner," and when physicians become decision makers for patients, "it is unclear how they should balance the task of 'serving two masters.'"[18] Physicians can also have financial conflicts of interests that could, for example, "lead to overtreatment of patients in fee for service reimbursement models."[18] Additionally, Volpe and Steinman note that end-of-life decisions are not simply medical but "social and ethical decisions" that, if left to the physician alone, would implicitly suggest that such profound end-of-life decisions are merely "choices [that] are reducible to medical facts."[5]

Nevertheless, there are strong advocates for the physician approach. Courtwright and Rubin note that physicians' knowledge and skill, coupled with their "fiduciary duties" to the patient, make them ideal decision makers for the unrepresented, as the fiduciary duty that physicians naturally uphold "obligates them to act as the surrogate decision maker."[2]

Supporters of ethics committees believe that they are less susceptible to conflicts and biases than physicians,[2] although risk of bias is associated with ethics committees as well. For example, as Magelssen et al note, ethics consultants may get "incentives to provide guidance that comports with the interests of hospital management."[19] Courtwright and Rubin also note that "there is no obvious reason why an ethics committee would more accurately represent an unrepresented patient's wishes than a treating physician."[2]

A recent development in hospital policy and law is a tiered approach, which applies aspects of both the physician and the ethics committee approach in decision making for unrepresented patients. In the tiered approach, treatments and procedures are assessed and assigned to one of 3 risk categories—low-risk or routine treatment, major medical treatment, or life-sustaining treatment—as a basis for decision-making policy.[1] For example, a physician may make decisions regarding low-risk treatments that are routine and in keeping with accepted medical practice standards. For medium-risk procedures that would normally require written informed consent, a physician might be required to consult with another physician or an ethics committee. The highest-risk or highest-stakes procedure, typically deemed to be withdrawing or withholding life-sustaining treatment, might require a physician to get approval and consensus from an ethics committee. These examples give a rough sketch as to how a tiered approach might

function—the exact parameters and requirements vary. For example, Colorado, New York State, and Montana have instituted statutes with a tiered approach similar to that just described.[1,4] The Cleveland Clinic has also generated a similar institutional policy based on 3 risk categories: routine care, decisions for which informed consent would ordinarily be needed, and decisions about withholding or withdrawing life-sustaining treatment.[20] Smith and Luck describe the Cleveland Clinic policy as a "gradation of various safeguards" put into "place as the significance and consequences of the clinical decisions increase."[20]

Conclusion

A collaborative, multidisciplinary approach to the problem of unrepresented patients, although imperfect, is preferable to a unilateral approach. As Moye et al argue, "collaboration is key to illuminate their [unrepresented patients'] needs and rights," while providing a "menu of options" that involves all 3 of the major decision-making approaches: physicians, ethics committees, and guardianship.[15] Taking this collaborative approach (which includes guardianship) and combining it with a tiered approach (which strikes a balance between physicians and ethics committees) creates a multifaceted decision-making method, involving layers of options and ethical safeguards, thus making it likely the best possible solution to this most vexing of bioethical quandaries.

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HEALTH LAW

Regional Unrepresented Patient Advocacy Committee as an Alternative for Decision Making

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Abstract

Acute care hospitals and extended care facilities across the United States care for patients who lack capacity to make medical decisions. When such patients are hospitalized and have no identifiable surrogate, their unrepresented status prompts questions about who should make decisions. This article explores using a regional state unrepresented patient advocacy committee as an alternative to appointment of a legal guardian or to using clinicians as decision makers.

Need for an Alternative

Acute care hospitals and extended care facilities across the United States care for patients who lack capacity to make their own health care decisions. Such patients might not have an advance directive for health care and might lack friends or family members who could act as surrogate decision makers on their behalf; these patients are unrepresented. This article examines the demographic profile of unrepresented patients and the variation in specific state and federal laws and in organizational policy regarding medical decision making on behalf of unrepresented patients. It also explores an alternative to using clinicians as decision makers or appointment of a legal guardian—namely, creating unrepresented patient advocacy committees (UPACs).

Patient Population Profile

In the United States, 71% to 80% of adults do not have any form of advance health care directive,[1] and, as DeMartino et al note, the "prevalence of decisional incapacity approaches 40% among adult medical inpatients and residential hospice patients."[1] In addition, Margolis and Verdery have shown that between 1998 and 2010, "6.6% of US adults aged 55 and above lacked a living spouse and biological children and 1% lacked a partner/spouse, any children, biological siblings, and biological parents."[2] This study also reported that having no spouse and having few living family members "are among the social factors most positively associated with nursing home placement."[2]

The challenge to the right to make one's own medical decisions extends beyond impaired capacity to do so, especially among members off the growing elderly population in the United States, many of whom reside in long-term care facilities. These individuals may

be able to make simple decisions related to their care (food preferences and acceptance of medications, for example) but lack capacity to make more serious health care decisions. Moreover, elderly patients might outlive family members or friends who may have known their preferences, similar to homeless patients who lack the ability to give informed consent and who have no contact information for family or friends. When these patients come to the hospital, it is likely that their treatment team will not know them personally or have any information regarding their treatment wishes or their personal values. End-of-life-care decision making becomes complicated for elderly unrepresented persons, as many of them (up to 70%) lack decision-making capacity near the end of life.[3] How and by whom are treatment decisions for this group to be made?

Decision Making for Unrepresented Patients

Many unrepresented patients enter the health care system via the emergency department as a transfer from an extended care facility or are brought by ambulance to the nearest hospital through the emergency medical system with no contact information for family or friends. In such cases, treatment commonly begins under so-called emergent implied consent. (Most state statutes include language that assumes a reasonable person would want medical care in an emergency.[4]) The patient is admitted and the treatment algorithms related to emergent care continue until there is a need for legal informed consent for a treatment or discharge plan. Then the hunt for a legal decision maker begins.

The process of finding a legal decision maker usually begins with a review of institutional policy that follows the relevant state law—in states that have such laws—regarding health care decision making for unrepresented persons. Often the institutional social worker starts a search for family members or friends of the patient. A patient might lack the capacity to make informed decisions and consent to health care treatment, but if he or she is able to communicate any information regarding family or friends, or if there are any personal belongings that might offer such information, further exploration of these leads is needed. If this initial search offers no useful information about a possible surrogate, a clinical ethics consult or discussion with members of the institutional ethics committee is often pursued. Most health care institutions have some form of clinical ethics support for both patients and clinical staff, including assistance and advocacy related to institutional policy dealing with naming a legal decision maker for persons who are unrepresented. When a search for family or friends reveals that the patient is truly unrepresented, the institution usually will begin the process of having a legal guardian named for the patient.

According to a 2018 study by the American Bar Association (ABA) Commission on Law and Aging,[5] 40 US states (and the District of Columbia) "have passed statutes regarding health care decision making for patients who lack capacity and have nothing in writing naming a person to make health care decisions for them."[5] The study identifies 3 general

categories of states: those that (1) specify a hierarchy—a list of potential surrogate health care decision makers (38 jurisdictions), (2) authorize surrogates but do not specify a hierarchy (2 jurisdictions), or (3) make no statutory provision (11 jurisdictions).[5] It is worth noting that some states include the attending physician in the hierarchy of potential surrogate decision makers.[5] In cases of conflict among surrogates (eg, several adult children), "the last resort for resolving conflict in every state is guardianship or conservatorship."[5] Although 40 jurisdictions have a statute regarding decision making on behalf of unrepresented patients, the ABA survey noted that 39% of respondents, who were members of the Society of Hospital Medicine and the Society of Critical Care Medicine, reported that they were not aware of any institutional policies regarding health care decision-making policies for patients who do not have a written advance directive in their institution.[5]

Guardianship

State guardianship is usually the last resort for naming a legal decision maker for unrepresented patients because it takes time and costs the institution thousands of dollars for each guardianship petition process (L.K.A-S, unpublished data, 2019). It is when the patient is ready for discharge from an acute care setting that clinical staff often notice the need for guardianship placement for the unrepresented patient. For example, a legal decision maker is needed to give consent for the patient to be transferred to a facility that provides less acute care, such as an extended care facility,[6] which is often the case. Because clinical staff may not be aware of the legal guardianship process or the time it takes for appointment of a guardian, the guardianship petition process often begins at the time the patient is ready for discharge. Bandi et al report that in their study the "median time between documented incapacitation and guardianship request (resulting in appointment of a temporary guardian able to make decisions for the patient) was 14 days."[6] This finding suggests that discharge of the patient was delayed because the petition for guardianship happened near the point of discharge. This legal process not only costs the institution thousands of dollars, with estimates running between $6000 to $10 000 for each petition depending upon the institution (L.K.A-S, unpublished data, 2019), but also can delay discharge for several extra days, which contributes to thousands of dollars in Medicaid and Medicare resource waste.

Need for Ongoing Advance Directive Review and Revision

Since most states have legal processes in place to help identify a legal decision maker for a person who lacks decisional capacity—with the last resort being legal guardianship[5]—why are so many patients without any kind of advance care plan, such as a power of attorney (POA) for health care? Although this question cannot be answered here, I will address 2 related questions: Who is responsible for helping people document their health care wishes in advance of illness or dementia? And what alternatives are there for persons who outlive their named POA for health care or who never had capacity to name one no matter what form was used?

There is a general consensus that the best place to have advance care planning conversations is in the outpatient setting when the person is not seriously ill and where the discussion can be had without being hurried along, as if the advance directive was just one more form to sign. Advance care planning conversations are now a billable service for patients with Medicare and Medicaid,[7] which provides a positive incentive for clinicians to spend extra time having these important conversations regarding patients' end-of-life care wishes. However, even with advance care planning, there will always be patients because who lack decisional capacity and are unrepresented because they have outlived their family and friends, no longer have a relationship with family members or friends, or are homeless with no contact information for family or friends.

Alternatives to Guardianship

The following is a list of surrogates for unrepresented patients as an alternative to legal guardians.

1. Attending physician, often in consultation with another physician, makes medical decisions for patient using the best interest standard, as patient values and wishes are not known[8];
2. Attending physician, along with institutional ethics committee representatives, makes decisions[9];
3. Institutional ethics committee chair and committee subgroup make decisions[10];
4. Regional unrepresented patient advocacy committee participates in decision making.

The fourth option has several advantages. A regional unrepresented patient advocacy committee or UPAC (in place of a state guardian) allows for a quick response from a committee made up of multidisciplinary health care professionals as well as a community advocate who review the patient situation and goals of care with treating team members making health care decisions, often end-of-life care decisions, on behalf of the unrepresented patient. Each UPAC would interact with the health care institution's ethics committee as well as treating team members and other institutional stakeholders in this process. The UPAC's role would be to review the patient's current medical information with the treating physician(s) and assist with medical and treatment decisions on behalf of the patient until a permanent legal decision maker is put in place.

These committees—which do not yet exist—would be organized by state governments with clear legislative and regulatory guidelines for transparency and by region depending upon population size, health care institutions, and demographics. Committee members would have background checks and an orientation similar to state guardians and would also have ongoing training related to their role as substitute decision makers. In addition, committee monitoring, oversight, and evaluation systems would need to be in place in order to maintain the trust of the public being served. More research needs to be done

regarding the exact logistics of setting up the regional committees as well as how a more permanent legal decision maker for unrepresented persons would be named. Nevertheless, the UPAC can be seen as an efficient short-term solution for what could be a long-term need.

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AMA CODE SAYS

AMA *Code of Medical Ethics*' Opinions Related to Unrepresented Patients

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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 patient[2]

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]

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POLICY FORUM: PEER-REVIEWED ARTICLE

How Should Unaccompanied Minors in Immigration Detention Be Protected From Coercive Medical Practices?

Giselle Malina

To claim one AMA PRA Category 1 Credit™ *for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming* AMA PRA Category 1 Credit™ *are available through the* AMA Ed Hub™.

Abstract

Current policies and ongoing border crossings have increased the number of unaccompanied minors and the length of time they spend in detention. The US Department of Health and Human Services Office of Refugee Resettlement and its detention facilities currently determine what constitutes appropriate medical care for unaccompanied minors in immigration detention. This care might not be in a child's best interest. In contrast, juvenile detention and human subject research regulations rely on child advocates and court orders to protect children from coercion and safeguard a child's best interest. It is urgent that the medical community advocate for these same safeguards to be put in place for the unaccompanied minors in immigration detention.

Immigrant Detention

From October 2017 through September 2018, more than 50 000 unaccompanied minors were detained while attempting to enter the United States at the border with Mexico,[1] and more are arriving every day. Most are fleeing violence in their home countries of Honduras, El Salvador, and Guatemala in the hopes of reuniting with family members and applying for asylum in the United States. Once in detention, these children are held for an average of 61 days before being released to local sponsors as they wait for their chance to claim legal status in immigration court.[2-5] With ongoing border crossings, stringent policies (recently eased) for the vetting of potential child sponsors, as well as the growing backlog in the immigration court system, the number of children and length of time they are held in detention is only likely to increase over the coming months and years. If the Flores Settlement Agreement[6]—the result of a class action lawsuit that outlined standards for the detention and release of unaccompanied minors in US custody—is replaced with new regulations proposed by the current administration,[7] it would, as Matlow and Reicherter note, "permit the detention of noncitizen children and

their families for indefinite periods in facilities without appropriate and independent monitoring,"[8] thus exacerbating the problem.

Health Care for Detained Children

In addition to having the medical needs normal to children, unaccompanied minors in immigration detention often have immediate medical needs related to malnutrition and vaccinations.[9] High rates of exposure to violence and trauma, as well as continued and prolonged detention, have also led to an increased need for medical and mental health care for anxiety, depression, and posttraumatic stress disorder.[10,11]

It appears there is no set process for ensuring that minors in immigration detention—who are noncitizens held in mostly private institutions—receive care that is in their best interest. And though the United States is the only country in the world that has not yet ratified the Convention on the Rights of the Child,[12-14] care of these minors should still be held to the best interest standard guaranteed by multiple state laws and upheld by courts across the country as well as the medical community at large.[15,16] Parents typically provide consent for medical treatment and serve as their child's advocate, and children who are wards of the state have court-appointed guardians. However, immigrant children lack these protections; there are multiple reports of shelters pressuring detained minors into consenting to medical treatments and medicating as many as 70% of their charges using psychotropic medication[17]—sometimes via forced injections—as a means of behavioral control.[17-19] Lack of appropriate informed consent in a shelter in Texas was so egregious that a federal judge ordered the government to obtain written informed consent by a surrogate authorized by court order before administering psychotropic medications, unless it was an emergency as defined by state law.[18] With no clear mechanism for unaccompanied minors to receive appropriate health care with the safeguard of informed consent, we must ask: What should informed consent look like for detained children, and which processes should be put in place to ensure that decisions are made in the best interests of each child?

Medical Decision Making

Private immigration detention centers have various contracts and regulations; there is apparently no standard policy for determining who is responsible for making medical decisions on behalf of detained children. The US Department of Health and Human Services Office of Refugee Resettlement (ORR) policy states that ORR-funded facilities housing children are responsible for initiating and implementing health care services, but there is no mention of who provides consent for children.[20-23] Few states have set more stringent standards for health care delivered in immigration detention facilities than the ORR. Thus, it is left to individual centers to decide what constitutes consent for those in their care, and it is unclear whether, or to what extent, children have any say in who

might make decisions for them or what happens when children disagree with those decisions.[20-22] But the interests of the ORR and detention facilities are not always aligned with the best interest of the child, as the reports of overmedication with psychotropic medications clearly demonstrate.

One model for obtaining informed consent for treating detainees is that used in juvenile penitentiaries. Traditionally, most states require parental consent for nonemergent procedures or treatment of minors in juvenile detention or court orders when those are not available.[24,25] Many unaccompanied minors currently in immigration detention are waiting to be released to local sponsors who must first be vetted and approved by the government.[26] These sponsors are often parents or close family members and thus the first persons from whom detention facilities should seek informed consent. However, sponsors might themselves be undocumented, and government policies that took effect in May 2018 required fingerprinting of a sponsor's entire household and allowed for information sharing with the US Department of Homeland Security Immigration and Customs Enforcement (ICE).[27,28] Subsequently, reports of detention of 170 would-be sponsors by ICE[29] led to a steep drop in sponsorship claims and an increase in the number of unaccompanied children with no clear point of contact for consent.[5,29,30] Although the policy has been scaled back, it still allows for ORR information collection and sharing with ICE.[28,31] As a result, the time a child spends in detention has lengthened considerably, with government data showing that the average time spent in detention has been as high as 89 days in the first 4 months of fiscal year 2019.[32]

When parents are not available to make decisions, and when the court system is bloated with long wait times that may significantly delay critical medical and mental health care,[33,34] how should consent be obtained? In most jurisdictions, teenagers are allowed by law to provide consent for some health procedures. Specifically, "Adolescents can consent to receive treatment for sexually-transmitted diseases, substance abuse, mental health disorders, or to obtain contraceptives or pregnancy tests."[35] At least 33 states and the District of Colombia have statutes allowing minors to consent for some outpatient mental health services, and in many of those jurisdictions, such as Virginia, this right has been interpreted to include consent for psychotropic medications.[17,24,36]

However, circumstances faced by unaccompanied minors make consent—and their rights to be free from undue influence—difficult to ensure. Facilities use a variety of pressures to get minors to "consent," such as in some facilities in which, as reported by *ProPublica*, the "Department of Homeland Security instructed staff to file a 'significant incident report' every time a teen refused to take medication.... That report could then be used to justify delaying reunification with family."[17] Pressures such as these can prompt teenagers to assent to medications and procedures to which they might not otherwise agree, and can be coercive enough to undermine typical standards of consent.[37]

The ideal of consent free from coercion has been a focus of many rules guiding human subject research among vulnerable populations, including incarcerated subjects. In scientific research involving minors in detention, it has become common practice to use child advocates to ensure proper consent is obtained.[38] Child advocates are defined as persons who act in a child's best interests, confirm the child's comprehension of implications of participating, and ensure that a child provides consent voluntarily, free from coercion.[38] Establishing a third party independent of the ORR and facilities detaining the children, whose sole responsibility is child welfare, seems a reasonable course of action. In fact, this is already being done. The Child Advocate Program was created under the Trafficking Victims Protection Reauthorization Act of 2008, which authorized the Department of Health and Human Services to "appoint independent child advocates for child trafficking victims and other vulnerable unaccompanied alien children."[39,40] However, this program was only able to serve 321 children in 2015.[40] In addition, the program advocates for children's "family reunification, release from detention, legal representation and the ultimate question as to whether the child will remain in the US or return to [his or her] home country."[41] In order to serve children's best interest as patients, the government and the medical community should advocate for expansion of this program—or other programs like it—to cover all children in immigration detention and to train advocates to defend children's best interests.

Advocacy

Medical community members should advocate for the application of juvenile detention and human subject research ethical standards to child detainees, especially when the number of unaccompanied minors and the amount of time they spend in immigration detention continues to increase. It is important that medical professionals voice support for child advocacy programs and decision-making processes free from coercion and undue influence. It's also worthwhile to remember that health care professionals treating unaccompanied minors in immigration detention centers are doing important work and that overhauling policies and adding needed resources could take years. In the meantime, the American Medical Association, other health professional societies, and the medical community at large must (1) urge policy changes that allow clinicians to refuse to provide nonemergent care to detained minors unless they can obtain consent free from coercion, (2) push for independent health professionals to be given access to audit care currently given in ORR facilities, and (3) ensure that health care of minors in detention receives the attention it deserves in the media and in current legal and policy discussions. Finally, it is important to remember that even though detained children are not US citizens, they are entitled to dignity, health, and decisions made in their best interest rather than that of the governmental agency detaining them.

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MEDICINE AND SOCIETY

Who Are "Unrepresented" Patients and What Count as "Important" Medical Decisions for Them?

David Ozar, PhD

Abstract

Unrepresented patients are hospital patients who lack decision-making capacity but have no advance directive and no one to serve as a legally authorized surrogate. An important first step in efforts to change the law and develop organizational policies that help respond to these patients' needs is determining which patients should be considered unrepresented and which aspects of hospital care should receive attention. This article proposes working definitions of *unrepresented* patient and *important* medical decisions based on the work of one statewide initiative, the Unrepresented Patients Project for Illinois.

Need for Policies Responsive to Unrepresented Patients' Needs

Everyone in health care wishes that every patient who cannot make important medical decisions has an up-to-date advance directive and a properly executed durable power of attorney for health care so that the patient's voice is as well represented as possible when important decisions need to be made. In the worst-case scenario, patients who lack decision-making capacity and for whom important medical decisions need to be made did not prepare an advance directive or other relevant documents about their preferences when they had decision making capacity and have no one to serve as their legally authorized surrogate. In the literature these patients are referred to as *unbefriended*, but the more common term now is *unrepresented*.

In most states, with only a few exceptions, there is only one legally authorized decision maker for such patients: a guardian *ad litem* is appointed by a judge to make medical decisions.[1] In most jurisdictions, however, this solution usually takes longer to implement than a treatment decision can be put on hold.[1] It is also expensive, and often guardians have heavy caseloads and know little about the patient.[1] In addition, unrepresented patients are typically cared for by physicians who rotate and whose views about proper goals of care and treatments for a given unrepresented patient can differ.

Ethical Issues in Medical Decision Making for Unrepresented Patients

Three major ethical concerns have been identified about how important medical decisions are being made for unrepresented patients in US hospitals.[2,3] The first concern is about the impact of the existing legal mechanisms (in most jurisdictions) on the timing of those decisions, which will need to be made from the moment a patient is admitted until—if ever—a guardian *ad litem* is appointed who interacts with the patient's attending physician(s), reports to the court, and so on. The second major ethical concern is that unrepresented patients are cared for by hospitalists or resident physicians who rotate (hence the word "attending" above) and who might have differing views about what constitutes proper goals or care plans—which can and do change as they rotate—raising important concerns about the continuity of care and potential arbitrariness of the treatment decisions that are made. The third major concern is about the complexities of determining what is in the best interest of a person about whose life values we know nothing or next to nothing.

A number of state legislatures have begun to consider these issues,[2,3] and, recognizing the absence of adequate legal responses, hospitals and health systems have also attempted to address these issues by means of organizational policies.[4] One policy-oriented program with which the author is affiliated is the Unrepresented Patients Project for Illinois (UPPI), which was initiated by members of the Institutional Ethics Committee of the NorthShore University HealthSystem,[5] a 4-hospital system primarily serving patients in Chicago's northern suburbs. As of this writing, UPPI has grown to include more than 100 individuals—hospital ethicists, ethics committee leaders, lawyers and administrators, and leaders of statewide organizations—representing 30 Illinois hospitals or systems and 15 other relevant Illinois organizations.

Defining *Unrepresented* and *Important*

With a view to proposing changes in the law or developing new organizational policies for the care of unrepresented patients, an important initial step is to determine precisely which patients should be considered unrepresented and which aspects of hospital care should be the focus of these efforts. The current UPPI working definitions of *unrepresented patients* and *important medical decisions* are offered below. These definitions are the product of research, email exchanges between UPPI members, and 3 in-person UPPI meetings held between April 2017 and April 2018. They are considered working definitions because adjustments and amendments are likely as specific organizational policies and changes in Illinois law are proposed.

Simply put, the goal of UPPI is to bring about changes in Illinois law to better address medical decision making for unrepresented patients. One change would be to enable court appointment of an in-hospital committee (or possibly individual) to serve as a legally authorized surrogate for an unrepresented patient (eg, as a guardian for health care) as soon as a patient is identified as unrepresented. Absent such legislative action,

hospitals or systems could enact policies that would enable such a committee (or individual) at least informally to partner with an unrepresented patient's attending physician(s) in determining the patient's best interest when important medical decisions need to be made for the patient and throughout his or her hospital stay (even as attendings rotate on and off).[6,7]

Definition of unrepresented. UPPI currently defines an unrepresented patient as meeting 5 conditions:

> A patient is Unrepresented who: (1) is facing an Important Medical Decision, and (2) is not capable of making an autonomous decision about this matter at the relevant time and is unlikely to recover this capacity before the decision needs to be made, and (3) has no advance directive and (4) lacks an identifiable substitute decision maker or legally authorized representative, and for whom (5) there is no other evidence from the patient's past or from other parties that is sufficient to support a reasonably conclusive judgment about what the patient would likely choose in the present situation if they were capable.

Regarding a patient's decision-making capacity (condition 2), this definition presumes that the usual ways of determining whether a patient is capable of autonomous decision making are sufficient.[4] However, if changes in state law or probate court practices are needed, the language of decision-making capacity in relevant statutes in each jurisdiction—including relevant mental health statutes and directives—will have to be taken into account.

Regarding the lack of an advance directive (condition 3) and a surrogate (condition 4), this definition presumes the adequacy of current criteria for due diligence by hospital staff. For example, members of a social work department are often charged with determining whether a patient might have a relative or friend who is able and willing to serve as a surrogate decision maker or if there is an appropriate advance directive or other indication of what the patient would likely choose if capable. It is important to note that there are reasonable limits to such efforts, including how much effort must be expended in trying to persuade someone to take on the role and responsibilities of a surrogate. Nevertheless, efforts to answer these questions are not sufficient if they do not go significantly beyond what is immediately obvious and readily available.

Regarding lack of knowledge of the patient's preferences (condition 5), due diligence obviously requires that previous organizations, caregivers, acquaintances, and so on (if identifiable) be contacted to try to help determine what is known regarding the patient's reaction to previous treatments or what the patient would likely choose in the present situation if he or she were now capable. For if we can reasonably conclude what the patient would likely choose in a particular situation if he or she *could* choose—even if the patient lacks an advance directive and a surrogate—there is broad consensus in the US health care ethics community, the legal community, and the public that this option should be selected. Admittedly, this situation is extremely rare, but it deserves mention

because what the patient would likely choose if capable is a standard (referred to as *substituted judgment*) that typically outweighs the best interest standard.[8]

As mentioned, since reasonably conclusive evidence of unrepresented patients' preferences is lacking, those making treatment decisions are therefore left trying to understand what is in their best interest.[1] We might call such determinations *bare human values judgments*—judgments that are supposed to be based on what is valuable to or constitutes well-being for a human, whoever he or she is. It is well known that adults differ in what they consider valuable in life or what constitutes their well-bring. Hence it is ethically problematic that whoever happens to be an unrepresented patient's attending physician may have to make important medical decisions alone—perhaps with personally chosen assistance—because there is no one to represent the patient. How best interest judgments ought to be made—which is widely debated in the bioethics literature[6]—is thus an important ethical consideration in caring for unrepresented patients, although rarely discussed in connection with this population.[7]

Definition of important medical decisions. UPPI also proposes the following as a working definition of *important medical decisions*:

> Important Medical Decisions are all the decisions about medical treatments and interventions that are neither emergent nor routine. Regarding emergent situations, the patient is presumed, both ethically and legally, to give implied consent for these. Routine medical interventions are those that do not require a formal act of consent because consent is taken to be implied when the treatment is in routine fulfillment of a plan of care that is based, in turn, on an already established determination of goals of care.

So defined, important medical decisions include decisions about treatments and interventions for which informed consent of either a patient or surrogate is required. It is important to note that the category of important medical decisions is not limited to decisions about instituting or ending life-sustaining treatments and other medical decisions at the end of life. In addition, this category includes decisions about determining or changing goals of care for a given patient and any decisions in which a plan of care to fulfill these goals is established or significantly changed. Obviously, an initial decision about goals of care for a patient is made soon after a patient's admission, even though there is often little explicit reflection on the reasons for and implications of such decisions because the focus is so often on determining a care plan. But since the latter depends upon the goals of care, determining goals of care is obviously an important medical decision, as are decisions to change goals of care or decisions to change a care plan that follows from those goals. Finally, important medical decisions include decisions regarding discharge for unrepresented patients who no longer need hospital care.

As noted, these definitions should be regarded as working definitions, because in any actual effort to formulate organizational policies or propose changes in state law,

existing definitions and policies will have to be taken into account. But the author offers them in the belief that they constitute a good beginning for better equipping the law, organizations, and caregivers to respond to the needs and vulnerabilities of unrepresented patients.

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MEDICINE AND SOCIETY

Who Should Make Decisions for Unrepresented Patients Who Are Incarcerated?

Matthew Tobey, MD, MPH and Lisa Simon, DMD

Abstract

The United States has a high incarceration rate. Incarceration is associated with increased risk for cancer, chronic illness, serious mental illness, and substance use disorder. People who are incarcerated are less likely to be offered or participate in advance care planning, less likely to document their treatment preferences, and might not have a surrogate if one is needed. This article explores medical decision making for patients who are incarcerated and unrepresented and considers advantages and disadvantages of different classes of decision makers for them.

Incarceration and Aging

Criminal justice reform has increasingly become a consensus issue over the past decade, with many jurisdictions working to overturn aggressive policing and hyperpunitive prosecutorial and sentencing policies.[1] Incarceration history is associated with poorer health and social outcomes,[2,3] so carceral policies regarding the care individuals receive deserve clinical and ethical attention.

The United States has the highest rate of incarceration in the world,[2] with the rate of incarceration of African Americans in state prisons being 5 times higher than that for whites.[4] At any given time, roughly 2 million Americans are incarcerated and 4.7 million others are under judicial control through probation and parole systems.[5] These 6.7 million individuals—2% of the nation's population[6]—are more likely than the average American to be members of racial or ethnic minority groups, be poor, have experienced homelessness, or have a serious mental illness, substance use disorder, or chronic medical illness.[4] Incarcerated people are also the only group in the United States with a constitutionally guaranteed right to health care.[7] When patients are incarcerated, physically isolated from family and community, and lack decision-making capacity and a surrogate, they are extremely vulnerable.

In addition, people who are incarcerated age at a faster rate than their peers (acquiring multiple comorbid conditions and dying earlier),[8,9] and the average age of people who are incarcerated is increasing[8] as a result of tough-on-crime legislation in the 1990s, which eliminated parole possibilities for those convicted of low-risk offenses. As these individuals become older and more frail, more attention should be paid to their treatment

preferences, values, and relationships with prospective surrogates before they lose decision-making capacity. For patients who are incarcerated and who don't have decision-making capacity or surrogates, we suggest strategies for identifying decision makers and responding to these patients' needs.

Restricted Liberty

Health care decision making is one of the few means by which people who are incarcerated can exert autonomy and independence.[10] Yet health care decision-making can be limited during incarceration, especially for decisions that could cause financial burden from a corrections management standpoint or cause harm to others in a correctional population.[11] Medical decisions can also become a form of protest or self-advocacy when people who are incarcerated refuse medication or treatment as part of a dialogue regarding other unmet needs or malinger to receive secondary benefits from engagement with clinicians.[10,12]

Health decision making can present unique difficulties for people who are or who have been incarcerated, including a lack of confidence about their health choices. For those who are still incarcerated, one reason for this lack of confidence could be a sense of futility about their ability to self-advocate in other domains of their lives.[13] Patients affected by incarceration might not feel comfortable speaking up about their symptoms or sharing important information when they visit emergency departments or are hospitalized, for example.[14] Concerns about discrimination can also contribute to the reticence of patients who were recently incarcerated,[15] as can limited understanding of their disease processes[14] or past experiences. On the other hand, correctional health care facilities have been observed to diminish patients' care choices by limiting available treatments and access to care.[16] Similarly, not all correctional settings allow individuals to complete advance directives,[14] and there is evidence that correctional clinicians have limited knowledge of the role of advance care planning.[17]

Identifying Possible Decision Makers

Because patients who are incarcerated face structural barriers to exercising their autonomy and developing trusting relationships, clinicians should approach with care situations in which such patients lack decision-making capacity, advance directives, or surrogates. Specifically, patients who experience incarceration and are nearing the end of life carry risk factors associated with not having an assigned decision maker.[18] Assigning a decision maker to represent the preferences of people who are incarcerated and incapacitated—or defining a statutory hierarchy of potential decision makers—presents a challenge. The Table describes the advantages and disadvantages of potential decision makers for unrepresented patients who are incarcerated in states or jurisdictions in which no explicit hierarchy of surrogates is specified by law.

Table. Advantages and Disadvantages of Potential Surrogate Decision Makers for People Who Are Incarcerated

Decision Maker	Advantages	Disadvantages
Family member	• Most common surrogate for nonincarcerated people, including analogous vulnerable groups (ie, homeless patients) • Common default surrogate in state statutes	• Increased rates of estrangement in incarcerated populations • Might not know patient's most recent desires or preferences
Correctional custodian	• Presumed proximity to patient and knowledge of patient preferences	• Potential conflicts of interest; financial and security concerns could supersede patient's best interests
Correctional clinician	• Sophisticated medical knowledge • Code of ethics to guide decision making and support beneficence towards patient	• Lack of knowledge of patient preferences • Potential conflicts of interest; medical resource considerations could supersede patient preferences
Friends both from "outside" and from the prison "family"	• Might have intimate relationships with patient • Prison "family" validates relationships cultivated in stigmatized and dehumanizing setting	• No system to ensure closeness of relationships

Family member. Because family separation comes with incarceration, a family member might not seem to be an appropriate surrogate. Circumstances surrounding an arrest and court processes can damage the close relationships of those in prison.[19] Substance use disorders and serious mental illness—both dramatically overrepresented in correctional populations[4]—can also exacerbate social isolation associated with fractured relationships. Moreover, if friends and family members share behavioral or social risk factors with a person who is incarcerated and incapacitated, they, too, might experience

incarceration, premature mortality, or—if suffering from a disorder—be deemed not to have capacity for making health decisions.

Despite these risks for those experiencing fractured relationships, family members remain likely surrogates for patients who are incarcerated and incapacitated. Homeless people estranged from friends and family members are a similarly vulnerable comparison group associated with fractured relationships,[20] and one study found that a family member was named as the surrogate decision maker in 87% of cases.[21] Another reason why a family member might make a suitable surrogate is that, despite the punitive nature of carceral policies and the risk of relationship fracturing, family integrity can persevere through an episode of incarceration. Men in prison, for example, experience similar rates of childrearing to the general population, even though by age 26, the marriage rate of men who have been incarcerated is over 50% lower than that of men who have never been incarcerated.[22] Although 22% of fathers and 15% of mothers in state prisons reported having no contact with their minor children,[23] the extent to which family ruptures render family member surrogates innappropriate is worthy of investigation and consideration. It should also be noted that regulations that limit visitation and privacy in the interest of security—both in correctional facilities and during hospitalization—pose additional barriers to an inmate discussing his or her preferences with potential surrogates.[24] Ultimately, selecting friends and family members as surrogates might be more complex for patients who are incarcerated than for members of the general population. Similar logic would also suggest a lower frequency with which the best decision maker would be a friend "on the outside" (ie, who is not incarcerated).

Correctional staff. Staff within a correctional or health care system are often named as alternate surrogates for patients who are incarcerated and incapacitated. Potential conflicts of interest can exist for employees, however, and can cause substantial ethical problems.[11] A correctional custodian, such as a prison superintendent, who serves as a surrogate might be biased by a desire to boost morale of other incarcerated persons or by incentives to limit (or increase) the duration or complexity of care.[14] Specifically, correctional health care professionals could be motivated to provide more care for financial benefit or to provide less care due to conscious or unconscious biases or beliefs. Potential for harm to patients who are incarcerated, incapacitated, and unrepresented suggests why many states have implemented statutes to avoid these kinds of conflicts of interest.[25] Many states, for example, accept (as a last resort) a signed statement from 2 attending clinicians who agree to make an important decision for an unrepresented patient.[26] Of additional concern is that both correctional custodians and correctional health care professionals could lack adequate knowledge of a patient's preferences, the most important duty of a surrogate.

Friends. A potentially appealing option for unrepresented patients who are incarcerated is for a member of the prison "family"—that is, a close friend who is also incarcerated—to

serve as surrogate. Social networks and relationships formed during incarceration can serve as sources of well-being and meaning.[27,28] People who are incarcerated serve health-related roles in some facilities—as prison hospice volunteers, for example—and can develop an intimate relationship with others who are incarcerated and nearing the end of life.[29] Many states' surrogate decision-making statues allow, in specified circumstances, a friend to serve as a decision maker,[26] which can be helpful and humane.

Selecting friends as surrogates for unrepresented patients who are incarcerated has 3 merits. First, it treats friendships formed in correctional facilities on par with those formed elsewhere, modeling respect for relationships forged among marginalized citizens. Second, it suggests the importance of expressing regard for the dignity of a vulnerable patient as a person connected socially to others who care about him or her. Third, it prioritizes the value of an incapacitated person's preferences over those of potentially uninformed clinicians, correctional personnel, or estranged family members.

Inclusive Responsiveness

The above Table is a guide only and not intended to suggest that default standards should be implemented without careful attention to the needs and treatment preferences of particular unrepresented patients who are incarcerated. States and other jurisdictions should not, for example, standardize or assign default decision-making hierarchies for persons who are incarcerated and lack decision-making capacity. Instead, the legal and medical communities should sponsor research to better understand these patients' needs and preferences. Current research on surrogate selection for people experiencing incarceration is sparse.[17,30,31] Without more robust input from key stakeholders, especially those who are incarcerated, health care professionals' ability to take good care of unrepresented patients who are incarcerated will be limited. Although the prospect of engaging an individual's prison family is promising, views of people actually experiencing incarceration should be gathered first.

We encourage clinicians and ethics committees faced with the not-uncommon dilemma of decision making for persons in custody to carefully consider pros and cons of possible surrogate decision-making candidates in states where a surrogate is not specified by law. When evidence of a patient's preferences is not available, a surrogate could be a close family member or a close friend—including from the prison family—or a carefully documented opinion from multiple health professionals could guide decision making. Regardless, the circumstances of a particular patient's case should be carefully documented and considered.

Due to aging among those incarcerated, the numbers of incarcerated persons unable to make health decisions in the United States will probably increase. Correctional systems should anticipate this trend and develop strategies for better advance care planning by soliciting patient input prior to loss of decisional capacity and formally assigning

surrogates. Clinicians, ethics committee members, and correctional personnel will continue to care for patients who experience incarceration, lack decision-making capacity, and for whom there is no evidence of their preferences. Future research on ascertaining these patients' treatment preferences can inform best practice development. Until then, considering potential surrogates—including family, friends inside and outside of correctional facilities, and health care staff—will require a patient-centered approach.

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