

Kristin Furfari, "Medical Decision Making for Unrepresented Patients: A Reflection on Colorado's Approach with Implications for Elsewhere," *The Journal of Clinical Ethics* 33, no. 4 (Winter 2022): 297-302.

Medical Decision Making for Unrepresented Patients: A Reflection on Colorado's Approach with Implications for Elsewhere

Kristin Furfari

ABSTRACT

Unrepresented patients are some of the most vulnerable patients encountered in the healthcare system today. One of the challenges associated with healthcare for unrepresented patients is the lack of a standardized legal approach to decision making for this highly vulnerable population. Current statutory approaches vary widely without best practices or consensus guidelines. In 2016, Colorado passed a medical proxy law that established a process for the appointment of an independent physician to serve as a temporary proxy decision maker for an unrepresented patient. Although this approach helps to identify a decision maker when no proxy is available, the appropriate standards for decision making remain uncertain. A peer-to-peer session at the Clinical Ethics Unconference in 2022 approached this conundrum with a focus on the best interests standard and the appropriate use of patients' context in decision making.

BACKGROUND

Unrepresented patients, defined as individuals who lack decisional capacity, lack advance directives, and lack an identified proxy decision maker to assist in making medical deci-

sions, are some of the most vulnerable patients encountered in the healthcare system today. Unrepresented patients are also referred to as "unbefriended patients," "adult orphans," or "incapacitated patients without surrogates" in the literature.¹ Healthcare ethics is focused on the balance of beneficence and patient autonomy in medical decision making—when patients lack capacity to describe their own values, goals, or perspectives, the balance becomes exponentially harder to navigate. These vulnerable patients, who are unable to state their own wishes and lack others to do so on their behalf, pose a tremendous challenge from an ethics and patients' rights perspective. As summarized by Thaddeus Pope, some commentators describe caring for unrepresented patients as one of the single greatest ethical challenges encountered in medical decision making and bioethics consultations.² The vulnerability of this population is profound.

Adding to the gravity of the situation is the sheer volume of patients that fall into this category. Unrepresented patients comprise a substantial percentage of patients in healthcare settings. Although it is difficult to accurately quantify the volume of unrepresented patients, estimates suggest that there more than 70,000 unrepresented patients in the United States.³ Studies by White and colleagues found that unrepresented patients made up 16 percent of patients admitted to an ICU in 2006, and 5 per-

Kristin Furfari, MD, is an Associate Professor in the Department of General Internal Medicine, Division of Hospital Medicine, University of Colorado, Anschutz Medical Center, in Aurora, Colorado. Kristin.Furfari@cuanschutz.edu
©2022 by *The Journal of Clinical Ethics*. All rights reserved.

cent of patients who died in an ICU in 2007.⁴ Another study estimated that unrepresented patients make up 3 to 4 percent of residents living in nursing home facilities.⁵ These numbers are becoming increasingly dated, and it is probable that they are increased now given the aging U.S. population. More recent data shows that unrepresented patients frequently interact with the healthcare system. Physicians report that they commonly encounter scenarios involving unrepresented patients—in a 2019 survey, almost half of surveyed hospitalists reported seeing at least one unrepresented patient per month.⁶

One of the reasons that healthcare for unrepresented patients is so challenging is because there is no standardized legal approach to decision making for this highly vulnerable population. Current statutory approaches vary widely without best practices or consensus guidelines. Although some professional societies including the American College of Physicians⁷ and the American Medical Association⁸ have attempted to publish policy statements regarding medical decision making for unrepresented patients, the statements are vague at best and do not offer practical stepwise approaches. The American Geriatric Society (AGS) position statement concludes that state-to-state variation causes confusion for healthcare providers and ultimately leads to patient harm.⁹ For this reason, the AGS advocates for “non-traditional surrogate decision makers” to address the challenge of unrepresented patients.

COLORADO APPROACH

In 2016, the State of Colorado took the AGS’s recommendation to heart and passed an amendment to Colorado’s medical proxy law that establishes a process for the appointment of a physician to serve as proxy decision maker for an unrepresented patient.¹⁰ This measure allows an independent physician to act as a temporary proxy for patients who are unable to make their own medical decisions when no other proxy is available. The law further outlines the responsibility of ethics committees regarding oversight, review, and documentation of the use of a physician proxy.¹¹ However, the logistics of identification, education, and support of physician proxies is largely left up to individual ethics programs. Given the large number of unrepresented patients seen in healthcare settings regularly, and the lack of clear guidance surrounding certain

logistics of the Colorado physician proxy statute, it is apparent that a consensus approach is needed to protect this vulnerable population and support the best interests standard.

A peer-to-peer solution sharing session at the 2022 Clinical Ethics Unconference in Atlanta, Georgia, brought together ethicists from different states and diverse healthcare institutions to address the challenge and brainstorm approaches to the pervasive conundrum of medical decision making for unrepresented patients. Instead of focusing on the benefits and challenges of the Colorado approach, the session targeted the more broadly applicable topics of the best interests standard and the use of patients’ context in proxy decision making, applicable in any state.

BEST INTERESTS STANDARD

One of the primary challenges in medical decision making for individuals without decisional capacity is to discern and respect patients’ values as a reflection of their autonomy. While patient-designated proxies are instructed to use the substituted judgment standard, aligning decisions with what patients would choose for themselves if they were able to do so, this becomes an impossibility in situations when patients’ values are unknown to proxies.¹² For this reason, physician proxies must use the best interests standard, basing their decisions on what is in the best interests of patients. This approach requires a more generic view of interests, without factoring in the idiosyncratic values of individual patients.

The goal of the best interests standard is to maximize benefits and minimize harms, but different decision makers may have different preferences, interests, or values and may, therefore, weigh the balance of risk and benefits differently. When viewed as an ideal goal, the best interests standard appears appropriate. However, critics of the best interests approach highlight the subjective and vague facets of this approach to medical decision making, which adds complexity to situations when patients’ values are unknown.¹³

However, the best interests standard still allows for certain values to guide decisions—in the case of a physician proxy, the values of the proxy *as a physician* become part of the equation. Physicians obviously have a more nuanced understanding of the medical scenario than nonphysician decision makers. This intimate understanding of medicine may ultimately alter

the decisions physicians make for unrepresented patients, since they view the situation through the lens of medicine and utilize their experience as healthcare providers. For example, research indicates that physicians receive significantly less intensive and aggressive end-of-life care than the general population.¹⁴ This is likely due to physicians' experience with end-of-life care in their own patients, which gives them a more nuanced appreciation of the burdens, futility, and financial aspects of aggressive care at the end of life. Additionally, physicians likely have a more sophisticated understanding of the alternatives to aggressive care, including palliative care or hospice. Physicians' views on life and death are colored by their role as physicians. By extension, a medical background likely informs the decisions that physician proxies make using the best interests standard.

The Unconference group agreed that although the best interests standard may not be perfect, it still seems like the most appropriate approach to unrepresented patients when their individual values and preferences are unknown. Proxy decision makers will use their own world-views and life experiences to analyze the balance of benefits and harms. Physician decision makers are no different—their life experiences are influenced by their role in healthcare, as opposed to something else.

This discussion highlighted the extreme vulnerability of unrepresented patients who are completely powerless and fully dependent on the healthcare team and proxy decision makers for their medical well being. For this reason, the Unconference group advocated that a healthy ethics committee be a requirement of any proxy decision maker process, with the goal of reviewing decisions, encouraging transparency of processes, and seeking patients' voices, as they are able. The AGS agrees with this approach, stating that when the best interests standard is applied to unrepresented patients, "institutional committees (such as an ethics committee) should synthesize all available evidence, including cultural and ethnic factors, during deliberations about treatment decisions."¹⁵

PATIENT CONTEXT

The appropriate use of patient-specific context, including cultural and ethnic factors as referenced by the AGS, raised robust dialogue within the Unconference group. While there was

group consensus that patients' context should be considered, potentially as a surrogate for individual values, the nuances of applying context to medical decision making led to significant debate. As already discussed, unrepresented patients are highly vulnerable and may also be the targets of social biases regarding the elderly, individuals with disabilities, individuals with mental illnesses, individuals with housing insecurity, individuals with substance use disorders, or immigrants and refugees, among other factors.¹⁶ Often, due to their underlying medical conditions and their social status as marginalized individuals, they are unable to advocate for themselves or to appeal decisions made on their behalf. And because they do not have identified interested parties to speak to their values, preferences, and goals, they are at the mercy of those who apply the best interests standard to their case.

Structural racism, bias, and stereotyping unfortunately infiltrate the healthcare system and influence the attitudes, behaviors, and expectations of healthcare providers, both at the conscious and unconscious levels. In 2003, the Institute of Medicine released *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, a comprehensive review of disparities in healthcare treatment that highlighted some of the impacts of structural racism on healthcare disparities.¹⁷ As explained in the report, some studies suggest that patients with racial and ethnic minority backgrounds are more likely than White patients to refuse invasive medical treatments. M. Gregg Bloche, a law professor at Georgetown University, states that, for many African Americans, doubts about the trustworthiness of physicians and healthcare institutions spring from collective memory of the Tuskegee experiments and other abuses of Black patients by largely white health professionals. This legacy of distrust, which, some argue, contributes to disparities in healthcare provision by discouraging African Americans from seeking or consenting to state-of-the-art medical services, is thus itself a byproduct of past racism.¹⁸

How then should context apply to proxy decision making? If an intubated patient physically appears to be Black, how should race factor into the decisions the proxy makes on the patient's behalf? The same question can be raised of any

patient with ethnic or racial minority characteristics or characteristics of certain religious groups or faiths. As we know, patients bring their own preferences, goals, and values to every healthcare encounter, and some of those preferences are socio-culturally determined. Should proxy decision makers attempt to acknowledge socio-cultural preferences as an expression of patient autonomy, even without knowing the unique preferences of the individual in front of them?

The concern that biases on the part of proxy decision makers will influence their decision making is founded. In a 1999 landmark study, Schulman and colleagues surveyed physicians' recommendations regarding vignettes of patients (actors) who presented with the chief concern of chest pain. The initial report found that physicians were less likely to recommend cardiac catheterization procedures for women and Black patients compared to men and White patients.¹⁹ A similar study that looked at physicians' management of renal colic found that male physicians prescribed twice as much hydrocodone to White patients than Black patients.²⁰

These studies, and many others like them, bolster the theory that physicians' diagnostic and management decisions are impacted by the race of their patients. By extrapolation, it can be assumed that decisions made on behalf of unrepresented patients, by physicians acting as proxy decision makers, will also be influenced by these same factors.

The complexity of this situation engendered robust dialogue by Unconference participants, and several suggestions were offered as a means to recognize and mitigate bias in proxy decision making. One suggestion was that proxy decision makers do not go to patients' bedside, but instead make all decisions in the absence of a visual image of patients, to mitigate biases that may be the result of physical characteristics. Patients could be referenced by initials only, so their name would not connect them to a certain racial, ethnic, or religious group, and gender-neutral pronouns could be used. In Colorado, this would be possible, as physician proxies are independent, nontreating physicians who are not involved in the direct day-to-day medical care of the patient. However, this suggestion raised concerns about the hypothetical and passive nature of decision making when patients are only initials instead of the living, potentially suffering individuals in a hospital bed. By stripping patients of all their

identifying characteristics, they become nothing more than a vignette on paper. For a group of already vulnerable individuals, this would contribute to a loss of self and further perpetuate the absence of autonomy. It is also important to recognize that, for some patients, the socio-cultural aspects of their identity that would be intentionally masked in the aforementioned approach are the exact aspects that do influence the healthcare decisions they would make, if able to do so on their own. By intentionally ignoring aspects of patients' identities, the best interests standard for decision making would become solely about medical considerations and not about the characteristics that makes each person unique.

POTENTIAL APPROACHES

Although this Unconference session generated more questions than solutions, consensus was achieved regarding several important points. First, it was agreed that ethics committees must have a robust presence when their institution cares for an unrepresented patient. The ethics committee should have the responsibility to guide processes, ensure transparency, and advocate on behalf of vulnerable patients. Proxy decision making for unrepresented patients requires a thoughtful approach, and ethics committees have the essential role of encouraging dialogue and offering diverse perspectives. Because ethics committees are generally multidisciplinary, a wide variety of expertise and perspectives can be represented by this approach. The Unconference participants did not agree that ethics committees themselves should serve as default decision makers, as has been suggested in the literature,²¹ but there was consensus that the involvement of ethics committees in these situations is compulsory. It is worth noting that the Colorado physician proxy legislation mandates involvement of the ethics committee to increase the level of protection for vulnerable patients and to support multidisciplinary efforts to hear the patient's voice.

One concern raised by the Unconference participants was that some ethics committees, especially those with limited expertise, insufficient resources, or less robust involvement may be unable to support the proxy decision making process in the ways described above. Certainly, there exists no consensus on membership standards and necessary training for members of eth-

ics committees broadly,²² and agreement about the best structure for ethics committees has not come to fruition since the Joint Commission mandate for the development of a “mechanism” to address ethical concerns.²³ For this reason, defined areas of inclusivity, competence, and knowledge for ethics committees that engage in physician proxy decisions is essential. This new role for ethics committees has potential to strengthen standards broadly and revitalize committees that struggle with uncertainty about their charge and responsibility.

The Unconference participants also supported the idea of education about bias and cultural awareness training for physicians (or others) who serve in the proxy role for patients who are unable to express their own preferences. This should include efforts to identify one’s own biases, focus on the patient as an individual human being, and allow time for reflection and adjustment of one’s perspective. Prospective proxies should be encouraged to recuse themselves from the role if they believe that bias about a patient’s context may influence their decision making. It may be helpful to include members from the community, either the patient’s identified community, if known, or the community surrounding the healthcare institution itself, to support inclusive, aware decision making.

CONCLUSION

Medical decision making for unrepresented patients is fraught with challenges, given the significant vulnerability of patients who are unable to make their own preferences known. While there is no national consensus about the best approach, all approaches involve ethical challenges regarding the appropriate standard for decision making and means to interpret patients’ unique context. The involvement of ethics committees is essential to support a thoughtful, transparent process in which diverse perspectives are recognized. Additionally, proxy decision makers should undergo bias education and cultural awareness training to minimize the potential contribution of harmful bias or stereotyping in the decision-making process.

NOTES

1. T. Pope, “Unbefriended and unrepresented: Better medical decision making for incapacitated patients without healthcare surrogates,” *Georgia State*

University Law Review 33 (2016): <https://readingroom.law.gsu.edu/gsulr/vol33/iss4/3/>.

2. *Ibid.*

3. *Ibid.*

4. D.B. White, J.R. Curtis, B. Lo, and J.M. Luce, “Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers,” *Critical Care Medicine* 34 (2006): 2053-9; D.B. White et al, “Life support for patients without a surrogate decision maker: Who decides?” *Annals of Internal Medicine* 147 (2007): 34-40.

5. N. Karp and E. Wood, “Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly,” *ABA Commission on Law and Aging* (2003): https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/human_rights_vol31_2004/spring2004/hr_spring04_incapacitated/.

6. D.M. Godfrey, “Health care decision-making during a crisis when nothing is in writing,” *NAELA Journal* 15 (2019): e1-16.

7. L.S. Sulmasy and T.A. Bledsoe, “American College of Physicians Ethics Manual: Seventh Edition,” *Annals of Internal Medicine* 1702 (2019): S1-32.

8. American Medical Association, *AMA Code of Medical Ethics Opinion 2.1.2*.

9. T.W. Farrell et al., “AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults,” *Journal of the American Geriatric Society* 65, no. 1 (January 2017): 14-5.

10. J.J. Glover, D. Bennett-Woods, and J. Abbott, “Colorado’s New Proxy Law Allowing Physicians to Serve as Proxies: Moving from Statute to Guidelines,” *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 69-77.

11. Colorado HB16-1101, <https://leg.colorado.gov/bills/hb16-1101>.

12. E.J. Emanuel and L.L. Emanuel, “Proxy decision making for incompetent patients: An ethical and empirical analysis,” *Journal of the American Medical Association* 267 (1992): 2067-71.

13. L.M. Kopelman, “Why the Best Interest Standard Is Not Self-Defeating, Too Individualistic, Unknowable, Vague or Subjective,” *American Journal of Bioethics* 18, no. 8 (2018): 34-6.

14. J.S. Weissman et al, “End-of-Life Care Intensity for Physicians, Lawyers, and the General Population,” *Journal of the American Medical Association* 315, no. 3 (2016): 303-5.

15. Farrell et al., “AGS Position Statement,” see note 9 above.

16. Glover, Bennett-Woods, and Abbott, “Colorado’s New Proxy Law,” see note 10 above.

17. “Unequal treatment: confronting racial and ethnic disparities in health care,” in *Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care*, ed. B.D. Smedley, A.Y. Stith, A.R. Nelson (Washington, D.C.: Board on Health Sciences Policy, Institute of Medicine, 2003).

18. M.G. Bloche, "Race and discretion in American medicine," *Yale Journal of Health Policy, Law, and Ethics* 1 (2001): 95-131.

19. K.A. Schulman et al., "The effect of race and sex on physicians' recommendations for cardiac catheterization," *New England Journal of Medicine* 340 (1999): 618-26.

20. C.S. Weisse, P.C. Sorum, K.N. Sanders, and B.L. Syat, "Do Gender and Race Affect Decisions About Pain Management?" *Journal of General Internal Medicine* 16, no. 4 (2001): 211-7.

21. A.M. Courtwright, J. Abrams, and E.M. Robinson, "The Role of a Hospital Ethics Consultation Service in Decision-Making for Unrepresented Patients," *Journal of Bioethical Inquiry* 14, no. 2 (June 2017): 241-50.

22. D.B. White, A. Jonsen, and B. Lo, "Ethical challenge: When clinicians act as surrogates for unrepresented patients," *American Journal of Critical Care* 21, no. 3 (2012): 202-7.

23. S. Caulfield, "Health Care Facility Ethics Committees: New Issues in an Age of Transparency," *American Bar Association: Human Rights Magazine*, 2007, https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/human_rights_vol34_2007/fall2007/hr_fall07-caulfi.