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Refusal of Representation in Advance Care Planning: A Case-Inspired Ethical Analysis

Andrew T. Peters and Joshua M. Hauser.¹

Short summary.

In this article A. T. Peters and J. M. Hauser explore ethical considerations relating to unrepresented patients. Their focus is on how to manage situations where patients decline naming a surrogate decision-maker in conversations around advance-care-planning. Two cases from the U.S. Department of Veterans Affairs hospitals are outlined and explored. The authors develop the concept of ‘informed refusal of representation’ and explore physicians’ ethical obligations in this context.

Introduction

An *unrepresented patient* is a patient who has lost capacity and for whatever reason does not have any identified surrogate decision-maker in place. Being unrepresented makes a patient more vulnerable to both overtreatment and undertreatment. Physicians may feel it is necessary either to continue treatment, or to withhold invasive treatment in the absence of a surrogate decision-maker to provide consent on behalf of the patient.

The authors outline two vignettes pertaining to patients declining to identify a representative during the advance care planning process for different reasons. The first vignette features a 90-year-old man who presents in primary care with symptoms of serious illness. The second vignette features a 70-year-old man with COPD presenting in acute inpatient care with severe pneumonia. Both patients have capacity and are likely to face serious declines in their conditions. In the advance care planning conversations they each refuse to appoint a representative, and ask instead that the physician or the hospital decide for them if they lose capacity.

Key Arguments

Unrepresented, not unbefriended.

In both cases the patient had relatives or friends that could be involved as surrogate decision-makers, but the patients themselves did not want them involved. The authors demonstrate that this is a relatively common scenario and that the majority (62%) of unrepresented patients are not unrepresented because of extreme isolation but because they don’t regard their social contacts as

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appropriate to make health care decisions for them. Data shows that many unrepresented patients are willing to identify a surrogate decision-maker if the issue is adequately explored, and the authors support the idea of incorporating ‘diligent search’ for an acceptable surrogate decision-maker in advance care planning conversations with unrepresented patients.

The informed refusal of representation

The authors distinguish between substitute decision-making and surrogate decision making. The former refers to substituted judgement (choosing as the patient would choose for themselves based on wishes and values), whereas the latter refers to decision-making based on the patient’s best interest without necessarily having knowledge of a patient’s preferences or values. While many of the patient’s wishes and values can be recorded in the advance care planning, situations are likely to occur where there is a need for a surrogate decision-making. The authors also recognize that a small portion of unrepresented patients may still chose to decline identification of a representative. When deciding whether or not to identify a social contact as a representative, patients should weigh whether having this social contact making decisions for them would place them at greater risk of harm than if decisions are made by someone who do not know the patient at all. The authors argue that if a patient can demonstrate that they understand the implications associated with not having a social contact making decisions for them, and still refuses to identify someone as their surrogate decision-maker, they are essentially providing informed refusal of representation (IRR).

Physicians as proxies

Approximately 80 percent of unrepresented patients have some decisions made for them by their treating physician, which, it is argued, seems ethically equivalent to the treating physician acting as a surrogate. The arguments against physicians as proxies are many and include concerns about lack of due process, oversight and transparency, and potential conflicts of interest and vulnerability to biased decision-making. In addition to this, literature suggests that physicians are inferior to family members in predicting a patient’s wishes or preferences. However, it may be argued that most of these concerns apply to all substitute and surrogate decision-makers, as family members and friends have biases and conflicts of interest too.

The authors acknowledge that there may be situations where physicians can justifiably act as a health care decision maker if certain criteria are met. Such criteria are laid out by Philip Rosoff and Kelly Leong, and include having at least one consecutive year of established doctor-patient relationship, having encounters observed by third parties, and abstaining from higher-risk decisions (e.g. capacity assessment and consent to participation in research). Peters and Hauser highlight that the two IRR cases outlined in this article do not meet these criteria, because the patients did not have a long-standing fiduciary relationship with the attending physician. Instead, by declining identification of a surrogate decision-maker, the two patients are essentially expressing their acceptance of the health care provider’s decision. Peters and Hauser argue against this form of physician proxy.

Mechanisms for decision-making for unrepresented and incapacitated patients

In most U.S. jurisdictions, the approach to address situations with unrepresented patients is a court-appointed guardian. However, it is not uncommon to encounter a delay between the moment where the need for a guardian is identified and a guardian is appointed. During this time, other mechanisms to address the need for decision-making about the patient's treatment may include designation of a team of people who are not directly involved in the patient's care. It could also include a hospital ethics committee. Having a group making decisions on behalf of the patient has the advantage that it involves deliberation around the patient's best interest. In the VA where the two cases took place, a team-based decision-making approach is in place for patients with IRR and for unrepresented patients in general.

Towards Health Fiduciaries and Shared Decision-Making

One of the main problems with the existing mechanisms for decision-making for unrepresented patients is their reliance on 'best-interest' standards. Peters and Hauser suggest that a way to solve this is to introduce the concept of 'health fiduciary' i.e., a person who is trained and licensed to act as a substitute decision maker for patients who are otherwise unrepresented. The difference between a court appointed legal guardian and a health fiduciary is that the latter would be appointed directly by the patient during the advance care planning process. Once appointed, the health fiduciary could continue meeting with the patients to be updated as the patient's condition evolves.

Conclusion/Recommendations

Patients without a surrogate should be encouraged to identify a representative as part of advance care planning conversations while they retain capacity. Patients have the right to decline a representative, but IRR must reflect the patient's understanding of what refusal involves and the patient's understanding and reasons for refusal should be explored fully. The IRR should be documented. Patients with no relatives or social contacts should be encouraged to appoint a health fiduciary who can act as a surrogate decision-maker. If patients considering an IRR chose not to appoint a health fiduciary, they should understand that the decision-making between physician and surrogate will be primarily physician-led, but the physician should not serve as direct surrogate. Finally, the authors acknowledge that their approach is rooted in the context of a culture in America that places high value on autonomy. They highlight the need for more empirical research to develop a better understanding of the IRR and associated ideas and suggest a cross-cultural comparison of the ethics of the unrepresented.