ETHICAL CHALLENGE: WHEN CLINICIANS ACT AS SURROGATES FOR UNREPRESENTED PATIENTS

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Many hospitalized patients require a surrogate decision maker because they are too ill to participate in decisions about their medical care. However, some patients do not have anyone available to serve as their surrogate. These “unrepresented patients” are vulnerable by virtue of their incapacity and the absence of a loved one to speak for them. They often come from historically marginalized populations, such as the homeless, those with mental illness or substance abuse problems, and the socially isolated elderly. When unrepresented patients develop advanced illness, clinicians face ethical challenges regarding when, if ever, it is permissible to forego treatments that could conceivably extend life.

Difficulties in making end-of-life decisions for unrepresented patients have been documented in skilled-nursing facilities, general hospital wards, and intensive care units (ICUs). One-third of physicians who care for critically ill patients have acknowledged withdrawing life support in at least 1 patient who lacked decision-making capacity, a surrogate, and an advance directive. Approximately 1 in 20 deaths in ICUs occur in incapacitated patients without surrogates.

Although numerous approaches to decision making for unrepresented patients have been proposed during the last 2 decades—including ethics committee oversight, appointment of a hospital-based patient advocate as surrogate, or use of a lay member of an ethics committee—the dominant approach remains the “clinicians as decision maker” model. For example, in a recent multicenter study, 81% of life support decisions for unrepresented patients were made by the treating clinical team alone or in consultation with another attending physician. Hospital-level oversight of the decisions occurred in fewer than 20% of cases. There are 6 main ethical concerns that arise when clinicians serve as both the clinician and surrogate for a patient. We argue that treating clinicians have an important role to play in decision making for unrepresented patients, but they should not have sole decisional authority over life support decisions.

Arguments in Favor of Clinicians as Decision Makers

Several reasons might be offered in favor of giving clinicians authority to make life support decisions for unrepresented patients. Clinicians have a unique understanding of diseases, therapies, and the expected outcomes of treatment, all of which are essential to sound medical decision making. Clinicians are generally held in high esteem by society, and have a strong professional obligation to act for the benefit of their patients. Moreover, clinicians can make decisions in a timely fashion, minimizing the chance that procedural inefficiencies would lead to unwarranted delays in decision making.

However, there is an important conceptual distinction between clinicians’ involvement in a decision-making process and having sole authority over the final decision. Clinicians can play a strong advisory role—and thereby contribute importantly to the decisions—without having sole decisional authority. Below, we delineate the ethical challenge of these decisions and present 6 reasons why treating clinicians should play the role of “adviser” rather than “decider” for unrepresented patients.
The Challenge of Life Support Decisions for Unrepresented Patients

Historically, medicine’s central struggle has been to fend off premature death. Consequently, traditional medical ethics is heavily influenced by a default assumption that death is the overriding potential harm to patients. However, because of advances in medical technology, it is possible to maintain biological human life under circumstances in which many patients would prefer a treatment course focused on symptom management rather than life extension. Therefore, clinicians face 2 potentially conflicting obligations: to prevent premature death and to avoid keeping patients alive in health states they consider “worse than death.”

When patients are competent or have a surrogate, clinicians resolve this potential conflict by eliciting the patient’s individual life goals and treatment preferences, then recommending a treatment course that maximizes the chance of achieving those goals without being disproportionately burdensome to the patient. These decisions are heavily value-laden. Consequently, when patients are incapacitated, lack a surrogate, and have not completed an advance directive, it is impossible to know whether a particular patient would prefer to be allowed to die rather than, for example, be maintained indefinitely on life support in a profoundly mentally impaired state.

A Departure from the Norms of Medical Decision Making

Current norms of American medicine do not grant clinicians the authority to administer treatment to a patient without consent, except in circumscribed emergency situations in which the requirement for consent is waived. In all other circumstances, clinicians are expected to engage the patient or a surrogate decision maker in a dialogue about what treatments promote the patient’s preferences or best interests as defined by the patient. This dialogue generally includes a discussion of treatment options, as well as the risks and benefits of each. With the advent of shared decision making as an ethical ideal, the clinician’s role has evolved to include eliciting information about the patient’s values, sharing in deliberations, and providing treatment recommendations. The patient or surrogate has final authority to accept or reject the clinician’s proposed treatment plan.

Two features of this normative approach to decision making are noteworthy. First, medical decision making involves a process of communication between a clinician and surrogate. This conversation may be important in itself because it requires clinicians to explain the reasons behind their proposed course of treatment. The ensuing conversation may help identify ways the treatment plan can be improved to fit the patient’s goals and needs. Second, treatment requires authorization by the patient or a representative, generally a family member. This model reflects the importance in American bioethics of respecting patients’ interests in self determination (when patients have decision-making capacity) and in acknowledging the important role of the family in American society (when they do not).

Existing probate law illuminates contemporary notions of the physicians’ role in decision making. In many states even if a competent patient wishes to appoint his or her treating physician as a legal representative, he or she is barred from doing so. For example, the California Probate Code states that patients may not appoint as their surrogate their “supervising health care provider” or “an operator or employee of a facility” where they receive care. Thus, clinicians in the United States normatively play the role of adviser rather than decision maker for incapacitated patients. Arguing from consistency, clinicians should play a similar advisory role for unrepresented patients.

Uncertain Expertise, Complex Ethical Decisions

Deciding whether to continue or forego life sustaining treatment when no one is available to
Competing obligations occur when clinicians have 2 or more valid professional responsibilities that conflict. Increasingly, clinicians are perceived to have ethical commitments to individual patients and to society at large to manage resources in a cost-conscious manner. The American College of Physicians’ charter of medical profession codifies this dual commitment of physicians to the individual patient and society. When surveyed, many clinicians also believe there should be a revision of how resources are allocated in intensive care units, away from patients at high risk of death.

When a patient has a family member or partner acting as his or her surrogate, clinicians’ competing obligations are less problematic because the surrogate is primarily responsible for representing the patient’s interests. Clinicians’ recommendations, which presumably are influenced to some degree by their dual commitment, are generally not binding. When clinicians act as decision makers for their patients, it is unclear how they should balance the task of “serving two masters.” Situations will arise in which both obligations cannot be fulfilled.

A related but distinct concern is that clinicians’ real or perceived conflicts of interest may compromise their ability to act as decision maker for an unrepresented patient. The Institute of Medicine defines conflicts of interest as “circumstances that create the risk that professional judgments about a primary interest will be unduly influenced by a secondary interest.” In this setting, the primary interest is the well being of the unrepresented patient. There are at least 2 types of secondary interests that could create conflicts of interest. First, financial conflicts of interest could arise if clinicians’ financial interests could be affected by decisions. The potential conflict could lead to overtreatment of patients in fee for service reimbursement models, and undertreatment in capitated models.

Second, clinicians also face nonfinancial conflicts of interest in ICUs. ICU clinicians generally work as part of a multidisciplinary team. To some degree, their happiness at work depends on good relationships with colleagues. End-of-life care often causes disagreements and conflict among staff. Clinicians have an interest in maintaining cordial peer relationships and therefore in making decisions that will keep peace in the ICU. In light of the variable nature of unit cultures it is likely that this would push toward overtreatment in some institutions and undertreatment in others. Clinicians also have an interest in not acting in ways that are against their own values. A conflict may arise, for example, a clinician has a personal religious belief that there are certain circumstances in which it is impermissible to forego life-sustaining treatment, regardless of the patient’s preferences. Because conflicts of interest may affect decision making in unintentional and unconscious ways, it may be difficult for clinicians to reliably identify and internally manage these conflicts.

Potential for Unwarranted Variations in Care

Leaving decisions for unrepresented patients to individual clinicians creates the potential for similarly situated patients to receive very different treatment. Empirical evidence suggests that different physicians make widely divergent choices when presented with the same clinical situation about whether to discontinue life support for a critically ill patient. This variation appears to be related as much to the physicians’ personal characteristics as to the characteristics of the patients or their illnesses. Such variation in care for unrepresented patients is unwarranted and ethically problematic because justice requires that patients who are similar in ethically relevant ways receive similar treatment.
Apart from concerns about “between-clinician variability,” there is also evidence that, as a group, clinicians’ individual treatment preferences at the end of life are systematically different from patients’ preferences. For example, Rydvall and Lynöe\textsuperscript{36} found that, across multiple different scenarios, clinicians are much more likely to believe life support should be withdrawn than is the general public. Many unrepresented patients are homeless or marginally housed, and empirical data suggest that these patients tend to prefer more aggressive life-sustaining treatment than clinicians.\textsuperscript{37} In aggregate, these studies suggest that clinicians may not be well positioned to independently decide when to limit life-sustaining treatment if the decision is based on value judgments about quality of life.

From a psychological perspective, confronting death on a daily basis is one of the most difficult aspects of practice in ICUs. Robert Burt\textsuperscript{38} has written that “facing death is like staring at the sun” and clinicians may vary in how they shield themselves from the psychological intensity of the issue. If the medical decisions individual clinicians make for unrepresented patients vary according to how they cope with death this, too, may lead to unwarranted variation in care.

Lack of Procedural Fairness

It is generally not possible to know whether decisions made for unrepresented patients are ones they would have chosen themselves. Because of this inherent uncertainty about the correct substantive decision, the process by which the decisions are made assumes greater importance.\textsuperscript{39} Daniels\textsuperscript{40,41} proposed several aspects of procedural fairness that are applicable to the care of unrepresented patients: oversight by a legitimate body, transparency in decision making, appeals to rationales and principles that all can accept as relevant, and procedures for appealing and revising individual decisions in light of challenges to them. The locus of authority with surrogates and the dialogue between the clinician and surrogate satisfies many aspects of procedural fairness.

Treating clinicians may not be perceived to have adequate authority to determine whether to continue attempts at life support or to allow a patient to die. Moreover, when clinicians are not required to explain their decision making to others in a formal way, the requirements for transparency and appeals to reasons all can agree are relevant may not be met. The lack of transparency may be perceived as constructing a “cloak of secrecy around end of life decision making,”\textsuperscript{42} which might breed mistrust in the decision-making process. Finally, this approach does not allow a clear mechanism for appeal and review of decisions. Some may contend that the multidisciplinary nature of ICU care inherently creates transparency, reason giving, and review of decisions. However, empirical literature suggests that collaboration between nurses and physicians is far from ideal, and that nurses often feel excluded from end-of-life decisions.\textsuperscript{43,44}

A related type of procedural objection is that leaving decisions to treating clinicians may lessen the chance that institutions incrementally develop effective mechanisms to handle decision making through accumulated experience. A decision-making process organized at the institutional level may over time lead to more consistent, higher quality decisions for unrepresented patients.

Public Perceptions of a Trustworthy Process

It is important that the public view as trustworthy the process by which decisions are made for vulnerable individuals, including unrepresented patients. Many of these patients arise from historically marginalized groups who have been victims of high profile ethical misconduct in the past.\textsuperscript{45} Ad hoc decision making by treating clinicians may be mistrusted because it leads to less rather than more transparency, dialogue, and oversight compared to similarly situated patients who have a surrogate.

Potential Criticisms

Some may argue that explicitly disallowing decision making by treating clinicians devalues their role as an advocate for their patients’ well-being. We think this concern is misguided because clinicians are not currently granted such authority for any other group of patients. Others may argue that any approach other than having clinicians act as decision makers will be less efficient, more complex, and add strain to an already strained health care system. It is undoubtedly true that the “clinician as decision maker” model allows for very efficient decision making. In fact, these decisions can potentially be made more expeditiously than for patients who have surrogates. However, in light of the ethical
complexities, it may not be respectful to sanction a process of decision making that has fewer checks and balances than those for patients with surrogates.

Conclusion

Treating clinicians have an important role to play in making decisions for unrepresented patients because of their medical expertise and their obligation to act for their patients’ good. However, serious ethical problems arise when they are asked to exceed their socially sanctioned role of adviser to also be the sole decision maker. The best answer to the question of “who will decide if not the clinician” remains unsettled. Our opinion is that, at a minimum, multiple perspectives and disciplines should be brought to bear on decisions for unrepresented patients, including ethics consultants, patient advocates, and clinicians. Authority for decisions should be with someone other than the treating clinicians, and perhaps someone not encumbered by relationships with the institution and the clinicians involved in the case.

Moreover, the approach to decision making should incorporate elements of procedural fairness, such as legitimacy, reason giving, transparency, oversight, and potential for appeal. We hope that a clear understanding of the shortcomings of treating clinicians acting as sole decision makers will provide the impetus needed to develop innovative alternatives. The maxim commonly invoked by philosophers also rings true here: “The test of a civilization is in the way that it cares for its helpless members.”

FINANCIAL DISCLOSURES

None reported.

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Am J Crit Care 2012;21 202-207 10.4037/AJCC2012514
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