

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 of 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 guardianship⁵—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 known⁸;
2. Attending physician, along with institutional ethics committee representatives, makes decisions⁹;
3. Institutional ethics committee chair and committee subgroup make decisions¹⁰;
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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