How to Protect Vulnerable Patients Admitted to Hospitals without Legal Guardians

Lisa Kay Anderson-Shaw, University of Illinois at Chicago

All too often, hospitals across the United States take care of adult patients who lack the capacity to make their own medical decisions -- and who are on their own, without a friend, family member, or any other decision-maker authorized to speak on their behalf. The number of these types of patients is on the rise and the current guardianship process is inefficient and often started too late after the person is hospitalized. This means that the United States' most vulnerable and powerless patients often do not have a legal decision maker until they are ready for discharge. Without a legal decision maker for a patient, medical staff are forced to make decisions based on what they believe is in the best interest of the patient without knowing about the person's values or preferences about treatments.

Patients without a legal surrogate or guardian – known as *unrepresented patients* – are often relatively powerless or poor people such as isolated elderly people, individuals with mental illness, or people with substance misuse issues. Furthermore, a large portion of unrepresented patients are homeless and face an array of health challenges associated with their lack of stable housing beyond their lack of representation.

The Current Guardianship Process is Wasteful and Slow

In most cases, when an unrepresented patient is admitted, hospitals are forced to seek a legal guardian for that patient through a state guardianship process. Frequently, the process is slow and lengthens the time the patient must stay in the hospital. In turn, unnecessarily long stays impose extra expenses on Medicaid and Medicare resources and cost healthcare institutions thousands of dollars each year.

Several converging trends underscore the urgency of this problem. The elderly population is growing and a high percentage of nursing home residents have some degree of cognitive impairment. Simultaneously, patients with dementia are on the rise, and a substantial number of these incapacitated individuals have no willing or available relatives or friends.

Elderly patients often lack representation because they have lost their ability to make medical decisions following admission to a long-term care facility. Many unrepresented, elderly patients at one point had surrogates or family members with power of attorney, but have now outlived their designated representatives, leaving them vulnerable and without proper representation.
Nearly four percent of U.S. nursing home residents are unrepresented – and they are the people most harmed by the inefficient systems hospitals currently use for arranging new legally empowered medical representatives. Many critical, health care decisions have to be made while hospital staff members await the completion of the cumbersome state process for arranging guardians for unrepresented patients.

Such decisions fall to physicians and other responsible medical staff members, who are must make high-stakes medical choices about “do-not-resuscitate” orders, the withdrawal or limiting of life supportive care, surgical interventions, dialysis, and invasive tests and procedures. Although the public trusts that medical professionals will make health care treatment decisions that are in the best interest of the patient, without a friend, family member or guardian to speak for a person unable to make his or her own decisions, there is no reliable method for assuring this is always the case. In addition, making these decisions for unrepresented patients places added pressure on caregivers in already stressful work environments, contributing to physician and provider burn out.

**A Better Approach – Regional Unrepresented Patient Advocacy Committees**

New bodies called “regional unrepresented patient advocacy committees” offer a promising alternative to the current state guardianship process for unrepresented patients. These committees are organized by state governments to respond quickly when an unrepresented patient enters the hospital, thus decreasing the strain on Medicare and Medicaid and reducing the waste of hospital resources during the delays typical in the conventional guardianship process.

Regional unrepresented patient advocacy committees balance the need for timely medical decisions with a thoughtful decision-making process. They also remove the possibility that physicians might have conflicts of interest in making important life or death choices for unrepresented patients.

To ensure every patient receives timely, thoughtful care in a system that considers their interests states should take the following steps in setting up these bodies:

- Set appropriate boundaries for each committee’s jurisdiction. Each body should take responsibility for a similar number of healthcare institutions and expect to deal with a similar number of cases – which will depend on the population of its jurisdiction and the proportions of vulnerable people living there.

- Require committee members to receive training similar to the instruction currently required for state appointed guardians.

- Require background checks and establish other safeguards to ensure committee members are qualified to serve the public in such a sensitive capacity.

- Establish clear legislative and regulatory guidelines that take the need for fairness, transparency, and public trust into account.

- Involve the staff of long-term care facilities in committee procedures. Because so many vulnerable patients come from long-term care facilities, their staff should learn about the preferences and values of residents while they are capable of making their own decisions. Later, if necessary, the facility staff will be able to convey useful information to the committee.