Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People

By Naomi Karp and Erica Wood

Editor's Note: The following article highlights key findings from Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly (ABA Commission on Law and Aging 2003), written by Ms. Karp and Ms. Wood with support from the Fan Fox and Leslie R. Samuels Foundation and in collaboration with the Samuel Sadin Institute on Law, Brookdale Center on Aging of Hunter College.

After ten years in a nursing home, an indigent eighty-nine-year-old Alzheimer's patient with no living relatives is admitted to the hospital with a high fever. Nursing home staff know of no friend or outside contact. Indeed, he has not had any visitors for many years. Doctors find the patient to be suffering from severe bedsores and a systemic infection and determine he is unable to make decisions about his treatment. The locale has no public guardianship program, and the state program is severely overburdened and underfunded. Without an authorized decision maker, how can hospital medical personnel provide treatment and determine the best course of action?

An eighty-four-year-old woman lives alone in a Washington, D.C., apartment. She had a professional career with the federal government until her retirement in 1990 and never married. Two weeks ago she didn't answer the door when her housecleaner arrived. When the building manager opened the door, he found the resident unconscious on the floor. The apartment was a mess, and the refrigerator was empty. Emergency room physicians found she was in a diabetic coma. She was admitted and stabilized, but a consulting psychiatrist says she has dementia and is not able to make healthcare decisions. Hospital discharge planners are unable to find a nursing home placement, although she has money in the bank, because no one is responsible for her. Should the hospital file for guardianship to facilitate long-term care placement?

According to a bioethicist at a major urban hospital, “The single greatest category of problems we encounter are those that address the care of decisionally incapable patients . . . who have no living relative or friend who can be involved in the decision-making process. These are the most vulnerable patients because no one cares deeply if they live or die.” The American Bar Association Commission on Law and Aging recently examined decision making for such patients in a 2003 report entitled Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly. The publication identifies the current state of law and practice in healthcare decision making for the unbefriended elderly and advances workable solutions that preserve their rights.

Background

Individual rights in healthcare decision making are rooted in the concept of informed consent, which is based on two principles: a patient has the right to prevent unauthorized contact with his or her person, and a physician therefore has a duty to disclose information so the patient can make an informed decision about treatment. If the patient cannot make such decisions, a surrogate authorized under state law can make them on the patient's behalf.

State laws offer four pathways for surrogate decisions, which Charles Sabatino of the Commission on Law and Aging characterizes as the four D's:

1. Directed decision making allows a person to specify certain decisions in advance in written
instructions, such as a living will.

2. Delegated decision making allows a person to delegate authority to an agent through a healthcare power of attorney; the individual maintains autonomy by specifying who will decide about treatment and which factors to take into account in the event of later incapacity.

3. Devolved decision making occurs under default surrogate-consent laws enacted in more than thirty-five states, which specifically authorize family members or others to make choices about treatment if no advance directive exists.

4. Displaced decision making refers to judicial intervention through guardianship or special court transactions; although guardianship can meet needs and offer necessary protection with court oversight, it removes basic human rights and can be costly and cumbersome. It is a last resort. In the study, we defined unbefriended elderly patients as those who do not have the decisional capacity to give informed consent to the treatment at hand; have not executed an advance directive that addresses the treatment at hand and have no capacity to do so; and have no legally authorized surrogate, family, or friends to assist in the decision-making process. For these patients, none of the above paths are available. As a result, the patients may be subject to overtreatment, undertreatment, or treatment that does not reflect their values or address their well-being.

Project Findings

The Commission’s report revealed the following findings:

Little existing study: Very few writings exist on healthcare decision making for unbefriended patients, and there are no previous in-depth studies. This reflects a sad lack of public attention to the needs of this vulnerable population.

Compelling estimated data: Hard data on the size of this population is lacking. Estimates differ, but all show the number is significant. Experts have speculated that nearly 3 percent to 4 percent of the total nursing home population is unbefriended. This coincides with observations made during our study, but the figures have no statistical basis. Broader demographic data show converging trends that underscore the urgency of the problem: the elder population is increasing, the number of individuals with dementia is increasing, a high percentage of nursing home residents have some degree of cognitive impairment, and a substantial number of incapacitated individuals have no willing and available relatives or friends and are in need of guardians or other surrogate decision makers.

Patient demographics: Unbefriended patients frequently are people who were socially isolated much of their lives. Often they fell through societal cracks into a no-man’s-land without traces of their pasts, preferences, and advocates. The majority are in hospitals or nursing homes and frequently have multiple chronic conditions that will require timely and wrenching decisions on major medical or life-sustaining treatment.

Existing legislative mechanisms: Our study identified four existing legislative paths to healthcare decision making for unbefriended patients:

1. Eight states have enacted statutory authorization for healthcare consent when no surrogate is available. These statutes designate default surrogates who have authority to make decisions without judicial action. Many of the provisions give a key role to the attending physician, either alone or in consultation with others, such as members of an institutional ethics committee.

2. Three states have enacted laws authorizing external committees of trained volunteers to make healthcare decisions on behalf of unbefriended individuals through an administrative hearing process.
These programs focus on people with mental retardation, developmental disabilities, and mental illness rather than on the frail, incapacitated, long-term care population, but are instructive as working models.

3. Many states and locales have enacted public guardianship programs for both healthcare and financial decision making for the unbefriended population. Public guardianship programs often are underfunded, understaffed, or simply unavailable, however. The need currently far outstrips the resources and will escalate with the aging of the population.

4. At least five states have enacted a court process to seek consent for healthcare or appointment of an individual to give consent, and additional states provide for a similar procedure by court rule. One judicial route provides for a temporary medical treatment guardian.

**Existing institutional practices:** When state law does not provide an available mechanism for surrogate decision making on behalf of incapacitated patients, healthcare institutions are left in a quandary. Our research identified three possible courses of action:

1. Some hospitals and nursing homes have ethics committees or procedures, but they generally engage in education, policy making, case consultation, and retrospective review—stopping short of decision making. Our study did review a few cutting-edge examples in which ethics committees do make decisions on behalf of unbefriended patients.

2. One large long-term care facility instituted an innovative, informal surrogate system to address the decisionmaking needs of potentially unbefriended residents.

3. Healthcare providers and institutions frequently develop their own ad hoc procedures for consent to treatment. Sometimes these rely on concepts of “administrative consent.” Sometimes physicians faced with critical treatment needs have nowhere to turn and simply go ahead and make the determination they think best, acting as an informal ad hoc guardian—following ethical dictates but skirting legal requirements.

**Project Recommendations**

In view of the findings, the ABA Commission on Law and Aging developed policy recommendations to ensure that solitary patients receive both medical and ethical attention. Selected recommendations of particular interest to lawyers concerned with individual rights and responsibilities include the following:

- Long-term care staff should play a greater role in investigating and conveying resident values and preferences. Direct-care staff in nursing homes and assisted living facilities can play a pivotal role in collecting information at an early point that will later be of great value to decision makers. They also can promote the use of advance directives where appropriate, which would narrow the scope of the problem. Facilities should encourage staff members, including nursing assistants, to communicate with residents and/or patients to learn their preferences; consider initiating “buddy” systems to pair staff members and isolated residents; and encourage communication with hospital personnel if residents are transferred for acute care.

- Long-term care facilities should develop procedures for collecting and using resident histories and values information. The federal Patient Self-Determination Act (1991) requires that facilities make residents aware of advance directives and document them. But facilities should go further and devise methods of learning, recording, and updating residents’ histories, values, and preferences before they are unable to transmit this information. If residents become incapacitated, this history can help shape good healthcare decisions.

- Healthcare professionals should improve techniques for assessing and enhancing patient decisional
capacity. There is no gold standard for assessing decisional capacity. Practitioners should not be too quick to label isolated patients as “incapacitated” based on communication problems, a diagnosis of dementia, or other characteristics; and they should recognize that capacity may fluctuate over time. Better interview and assessment tools could help practitioners recognize that patients may retain capacity to make basic decisions, and thus work to narrow the pool of unbefriended individuals.

- Facilities should develop and strengthen internal decision-making mechanisms, and states and communities should develop external bodies to make healthcare decisions for patients lacking surrogates. As our research indicates, cutting-edge efforts to develop decision-making models include internal institutional collaborative processes (e.g., ethics committees) as well as external committees (e.g., state-based surrogate decision-making committees). Each model has strengths and weaknesses. Continued experimentation can help refine and test their effectiveness and fairness. Hallmarks of well-designed systems include focus on the patient, freedom from conflicts of interest, emphasis on least-restrictive alternatives, promptness, cost-effectiveness, expertise, and accountability.

- States and localities should develop temporary medical treatment guardianship programs. More than a decade ago, advocates in New Mexico demonstrated a temporary medical treatment guardianship program using trained volunteers and an intensive decisional process with court oversight. They also crafted a Temporary Medical Treatment Guardianship Act. Although some states do authorize courts to appoint surrogates with the limited purpose of making designated healthcare decisions, the New Mexico program has not been replicated—nor has the model act been adopted by other state legislatures. Given the impending growth of the unbefriended elderly population, this model merits attention.

- States should support public guardianship programs that are adequately funded and staffed. Many states and other jurisdictions still lack public guardianship programs—the ultimate safety net for incapacitated people who are poor, alone, and unable to care for themselves. States that do have programs frequently provide insufficient support in appropriated funds. Guardianship is often frowned upon as a mechanism for healthcare decision making for the unbefriended elderly—too costly, too time consuming, overly cumbersome. Indeed, for individuals whose only need is a healthcare decision, the other mechanisms named in this report may be preferable. But public guardianship should be readily available for those in need, particularly when the decision making may be ongoing, when both healthcare and financial decisions are required, or when there is a risk of abuse. States must fund these programs. In turn the programs themselves must require that staff and volunteers are trained in bioethics and healthcare decision making, and must include specific guidelines for making surrogate treatment decisions. It is critical that public guardians emphasize strengthening autonomy and respecting individual values to the greatest extent possible.

Conclusion

The dilemma of finding workable decision-making mechanisms for unbefriended elderly patients is a difficult one. Lawyers focused on individual rights and responsibilities may want to experiment with approaches to assist this most vulnerable population. Some communities are exploring ways to follow up on the Incapacitated and Alone study. For example, an interdisciplinary group in San Francisco has started meeting to brainstorm ideas to help the city’s unbefriended elderly residents. They are examining alternatives such as a county-wide community ethics committee, increased and creative use of existing statutory remedies, and changes to state law. Judges, attorneys, public guardian staff, public officials, social service providers, and healthcare professionals are joining forces.

The importance of these efforts to isolated and incapacitated seniors cannot be overestimated. As one hospital ethicist emphatically explained, “We owe these patients the highest level of ethical and medical scrutiny; we owe it to them to protect them from overtreatment and from undertreatment; we owe it to them to be certain that they are not a statistic in a study that demonstrates that over 50 percent of patients who die do so in moderate to severe pain; we owe it to help them live better or to die in
comfort and not alone."

Stats: Health

- Percentage of seniors reporting “fair” or “poor” health, 2002: 27%
- 41.6% African American
- 35.1% Hispanic
- 26.0% white
- Percentage of seniors within the total population reporting a disability: 41.9%
- Most frequently reported impairments, 1996: arthritis, hypertension, hearing, heart disease, cataracts, and orthopedic problems
- Number of people age 55 and older using illicit drugs during previous 30 days, 2000: 568,000
- Number of people age fifty and older with problem substance use, 1999: 2,549,000
- Estimate of problem drinking among nursing home residents: 49%
- Average out-of-pocket health costs for seniors: $3,493
- Percentage increase this figure represents since 1990: 50%
- Additional life expectancy for those 65 in 2000: 17.9 years
- Average rate of suicide among seniors: 1 every 90 minutes
- Leading cause of death for seniors in 2000: heart disease


Naomi Karp and Erica Wood are associate staff directors of the American Bar Association Commission on Law and Aging. To order the Commission’s new report, Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly, contact abaaging@abanet.org or call 202/662-8690.

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