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In This Issue

The 'Unbefriended' Challenge PA/LTC

BY CHRISTINE KILGORE

Medical decision-making for unrepresented, or "unbefriended," nursing home residents is one of the most challenging problems in the broader realm of biomedical ethics and an issue that some nursing home leaders are trying to address, according to interviews with legal experts and medical directors across the country.

"Some state mechanisms work better than others, but in general, guardianship isn't working very well," and other legally sanctioned processes for making medical decisions in the absence of surrogates are either nonexistent or inadequate, said Thaddeus Mason Pope, JD, PhD, director of the Health Law Institute at Hamline University School of Law in Saint Paul, MN.

The void leaves nursing homes at times struggling to work with residents who do not have decisional capacity to give informed consent to treatment, advanced directives or Physician Orders for Life-Sustaining Treatments to provide instructions, or a legally authorized surrogate. One estimate is that 3%-4% of nursing home residents in the United States are unrepresented.

At a regional community ethics meeting late last year in Colorado, for instance, a panel discussion about advance directives in long-term care evolved into a discussion about how best to make tough decisions for unbefriended patients. "It's a huge issue for many facilities," said Gregory Gahm, MD, president of the Colorado Medical Directors Association and medical director of numerous Denver-area skilled nursing facilities.


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One estimate is that 3%-4% of nursing home residents in the United States are unrepresented by a surrogate decision maker.

As of last month, members of the community ethics group – nursing home administrators, physicians, hospice leaders, chaplains, nurses, social workers, attorneys, and others who meet regularly – were considering the idea of encouraging facilities to form health care decision-making "proxy groups." A facility would bring together the providers and front-line staff who have cared for an unbefriended resident – as well as a state ombudsperson, who would serve as an impartial observer – when that resident needed a treatment decision.

Currently, many decisions about care for unrepresented patients and nursing home residents are made by physicians alone. According to a 2012 report, some patients clearly prefer physicians over guardians as surrogate decision-makers, and 12 states accordingly authorize attending physicians to make decisions for unbefriended patients, including nursing home residents, either unilaterally or with a concurring opinion (J. Clin. Ethics 2012;23[2]:177–92).

Yet, in general, said Dr. Pope, who coauthored the report, risks of potential

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As Care Teams Cooperate, Silos Topple, Quality Rises

BY JOANNE KALDY

In the post–health care reform world, medical practitioners no longer can work without the input of other disciplines or specialties. The concept of care teams, with the patient at the center, is the new normal.

"Geriatrics always has been open to the interdisciplinary team and the idea that it takes a community to care for older adults. But now, with the rise of the [Affordable Care Act] and accountable care organizations, the focus on teams by policymakers and other decision makers is more than lip service," said Barbara Resnick, PhD, RN, a professor at the University of Maryland School of Nursing in Baltimore and longtime AMDA member.

Reflecting AMDA's long support for the team approach to care in postacute and long-term care (PA/LTC) facilities, the organization's House of Delegates in March formalized its commitment to including practitioners beyond medical directors in its programming, policy setting, and planning. At their meeting in Nashville during AMDA LTC Medicine—2014, the AMDA delegates voted to extend full membership to nurse practitioners (NPs) and physician assistants (PA) and to change the organization's name from AMDA – Dedicated to Long Term Care Medicine to AMDA – The Society for Post-Acute and Long-Term Care Medicine.

"Nursing home medicine always has been team-oriented.

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Ethics at Issue

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bias and conflict of interest when decisions are made by physicians alone outweigh the efficiency of unilateral decision-making. Some jurisdictions have formalized that viewpoint. New York State, he noted, authorizes physicians to make decisions for a patient but requires the concurrence of a second physician and sometimes an ethics consult, depending on the invasiveness and gravity of the treatment. The Veterans Health Administration follows a similar process.

Some nursing homes can't muster an internal ethics committee, but can turn to consultations with a nearby hospital's ethics committee or a regional body, such as the committees administered throughout New Jersey by the state's Office of the Ombudsman for the Institutionalized Elderly. AMDA has recommended since 1997 that each nursing facility should have an available "ethics mechanism," and an AMDA toolkit released last year details how to start and maintain a long-term care ethics committee.

Such committees – especially internal ones – rarely have legally sanctioned decision-making power, however. According to Dr. Pope, only five states have institutional, multidisciplinary committees formally empowered to make treatment decisions for unrepresented patients (and two of those states' laws address only hospitals). "The remaining states have no clear legislative or regulatory guidelines," he said in an editorial in the New England Journal of Medicine (N. Engl. J. Med. 2013;*369*[24]:1976–8).

In the absence of clear legislative or regulatory guidelines, "it is up to facilities to develop their own institutional policies" to ensure transparency and fair process for unrepresented patients, Dr. Pope wrote. "Providers have both the duty and the discretion to design these policies."

However, according to Robert Gibson, PhD, JD, a senior clinical psychologist at Edgemoor Distinct Part-Skilled Nursing Facility, County of San Diego, CA, a nursing home may be understandably reluctant to design official policies or committees without an existing legal framework in its state. When they do go it alone, nursing homes should ensure, to the extent possible and with legal counsel, if possible, that the mechanisms are consistent with local and regional standards of care and best practices.

Dr. Gibson's state, California, is one of the few that give legal authority to interdisciplinary teams in long-term care facilities to make medical decisions for incapacitated individuals with no known family or friends. California's statute was recently challenged, however, in a lawsuit by an advocacy organization contending that the statute is a violation of due process and has permitted nursing homes to improperly give residents psychotropic drugs, place them in restraints, and end life-sustaining treatment.

Dr. Gibson said the charges, filed last October, reflect some isolated instances of facilities' improper use of the statute, not a problem with the law itself. For instance, interdisciplinary teams may not have been made up correctly, or facility staff may have made choices for residents while disregarding available decision-makers. "If facilities don't use the statute in the right way and use it to do the right thing, it's open to attack," he said.

The team-based model works well, Dr. Gibson said, and can be successful for many situations, from obtaining consent for admission to a nursing home to a range of decisions, either affirming or refusing treatment.

Nursing homes are indeed in a quandary, said Colorado's Dr. Gahm, but "certainly there is a precluding interest for nursing homes to do something" to enable fair and thoughtful decision-making for the unbefriended. And, as he sees it, there is an advantage to collaboration: If facilities in a locale or region all "embrace common mechanisms, and the ombudsmen are on board, then you're not legislating, but you're [changing the culture and] setting standards," he said.

In all states, the judicial process for a health care facility to assume guardianship is slow, cumbersome, expensive, and a last resort at best, especially for nursing homes, several sources for this article said. The problem of the unbefriended weighs on Dr. Gahm's mind, which says something about the extent of it. Colorado is among the states with the most flexible default surrogate laws; the list of potential clinician-appointed surrogates includes not only close family and relatives but also friends. A longer list of potential surrogate categories should help reduce the number of unbefriended in the first place.

Like a few other states and jurisdictions, Colorado also has a program to train volunteers to serve as court-appointed guardians for the unbefriended. Yet, while Dr. Gahm said that the volunteers become highly competent to serve as surrogates, it is extremely difficult for nursing homes to recruit enough of them and sustain their efforts.

Joshua Raymond, MD, MPH, CMD, immediate past-president of the New Jersey Medical Directors Association, said that he has had positive experiences with state-appointed guardians. "They have advocated for the patient, and they've been reasonable, at the same time, with end-of-life decisions," he said.

However, ethics committees have advantages. Among other things, there are often long delays in obtaining guardianships, and the process is prohibitively costly for many nursing home residents. There appears to be a shift occurring, Dr. Gibson said, toward recognizing a "community approach" to substituted judgment, rather than vesting authority in one surrogate.

Dr. Pope called ethics committees "the best middle ground" for making treatment decisions for unrepresented patients. As a legal expert, he favors those that are external to the health care facility or nursing home.

Independent viewpoints provide a check on possible biases and conflicts of interest that clinicians have been shown to act on, even if not consciously or deliberately, such as those relating to age, race, or financial incentives to undertreat or overtreat. In addition, the need to explain treatment decisions to another decision-maker – especially an outside decision-maker – can prompt more thorough deliberation and clearer articulation of risks, benefits, and alternatives, Dr. Pope said. The mechanism being deliberated in Colorado, on the other hand, involves an internal team supplemented with an outside ombudsman for objectivity.

Dr. Raymond, who is medical director of The Manor Health & Rehabilitation Center in Freehold, NJ, said that either approach can be helpful. Certainly, he advised, nursing homes that are part of larger health care systems should utilize the professionals and resources of that system because forming and maintaining an ethics committee can be labor intensive. The main point, he said, is that the "physician should not be standing alone. You need to have resources available."

Sometimes, casting a wide net within one's facility is all that is needed, several sources said. "Most importantly, when making decisions on behalf of others, we should get input from as many available sources as possible," said Jonathan Evans, MD, MPH, CMD, adding that "those who have the most contact with residents generally have the most knowledge."

"It is very, very difficult to know exactly what someone else wants – even if you know that person well," said Dr. Evans, AMDA's immediate past president and chief medical officer for Life Care Centers of America in Cleveland, Tennessee. He said that numerous studies have shown that decisions that individuals say they would make for themselves under particular circumstances do not match decisions that their designated surrogates would make. "In general, adults tend to presume that their parents, for instance, would have wanted more aggressive care than they actually do," he said.

Looking at long-standing religious preferences, previous encounters with the health care system, past rejections and acceptances of elective interventions, and other factors can sometimes yield clues as to what the individual might want, sources said.

"Remember, too, that someone may be incapacitated in the sense that they can't give informed consent, but they may still be able to discuss, in some way and at some time, certain preferences and wishes," Dr. Gibson noted. "We need to look for anything that enables us to best execute substituted judgment."

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