Medical Ethics

By Jonathan Evans, MD, MPH, CMD

Delicate Issues of Sexuality in the Nursing Home

The Case

During the course of her routine afternoon rounds, a nursing assistant entered the semiprivate room of an 84-year-old male resident with moderately severe dementia. The patient himself was nonambulatory and required assistance with all basic activities of daily living. He was on a scheduled toileting program every 2 hours and wore an incontinence garment.

The nursing assistant knocked on the resident's door, announced herself, and, hearing no answer, turned the doorknob and entered. To her surprise and embarrassment, she happened upon a scene in which the male resident was lying in bed while another resident, a 72-year-old wheelchair-bound woman from another floor of the facility, was performing oral sex on him.

The nursing assistant, having never encountered a situation like this before, left the room in some distress and immediately contacted her supervising nurse. The nurse entered the room and interrupted the proceedings, to the apparent chagrin of the couple (who had not previously been observed socializing together). Subsequently, the director of nursing, the facility administrator, the attending physician, the medical director, the wife of the male resident, and the adult children of the female resident were all notified of the apparent change in each resident's condition.

When contacted by facility nursing staff, the medical director asked about the residents' decision-making capacity and whether there was any evidence of coercion. The director of nursing asked what the residents and their families thought. The administrator expressed concern about the gentleman's hygiene, while the female resident's attending physician, apparently concerned about patient safety, asked, "Was her wheelchair locked?" The family members contacted reacted to the news with responses, depending upon their individual perspectives, that ranged from shock and shame to anger, admiration, and muted joy.

After some investigation, it was felt that neither resident was coerced. Facility staff were provided in-service training on residents' rights, including the right to privacy as well as the right to freedom of movement within the facility. The care plans of both residents were reviewed and updated.

Discussion

Sexuality is a normal and healthy part of life for most adults, even late in life. For many people, however, it is difficult to reconcile the seemingly conflicting images of sex and nursing homes. This case touches upon a number of related issues.

Among them are patient autonomy; decision-making capacity; privacy; regulatory issues including the right to "attain or maintain the highest practicable level of physical, mental, and psychosocial well-being"; concern for patient safety; dignity; and the obligation of facility staff to protect residents from harm, including freedom from abuse or exploitation.

Conflicting Values

The idea of nursing facility residents engaging in sex is uncomfortable for many facility staff and for many family members of nursing facility residents. This discomfort may be further exacerbated by age bias. Something that may be considered normal for younger adults may be considered abnormal for their grandparents, even though their grandparents may strongly disagree. It may be difficult for some staff members to overcome their own emotions or even their own personal values regarding sexuality when suddenly confronted by situations such as the one described here, and to act solely in the interest of the people entrusted to their care. Sex among consenting same-sex residents may be even more difficult for some facility staff to accept or allow.

In addition to value conflicts between individuals, there may be one between a resident and an institution. Facilities with religious affiliations are guided by the values of their parent organization. These may include explicit policies regarding sexual expression and its propriety or lack thereof, which a resident may not share.

Patients with dementia may forget that they are married. They may mistakenly believe that another facility resident is a spouse. They may lack the cognitive ability to make complex decisions and yet have a strong sexual desire and a diminished ability to control sexual impulses. Sexual behaviors are basic, fairly primitive, and overlearned during a lifetime, while the social rules regarding sex, just like the rules regarding urinating in a bathroom instead of one's pants, may be long forgotten in patients with cognitive impairment.

Decision-Making Capacity

The standard for decision-making capacity varies as a function of the complexity of the decision to be made and the risks associated with the choices. More complex decisions, such as that to undergo a complex chemotherapy regimen, require much greater cognitive ability than the decision to accept a dose of pain medicine. The cognitive threshold for decision-making capacity regarding sex is considered to be fairly low. Moreover, while the psychosocial consequences of sexual activity may be quite complex, the decision to engage in sex may be driven more by emotion and biology than by intellect, even among individuals with normal cognitive function. In addition, physical desire and physical ability may persist despite cognitive incapacity.

In decades past, issues of sexuality in young adults with impaired decision-making capacity due to developmental disabilities or those considered "mentally unfit" because of epilepsy or another neurologic condition were approached very paternalistically. Many of these people were subjected to involuntary sterilization to prevent pregnancy. In more recent years in Western culture, autonomy has taken precedence over competing moral and ethical concerns.

Respect for Autonomy

Virtually everyone who lives in a nursing facility (even briefly) is there because they have lost some physical or cognitive capacity. In this circumstance, laws, regulations, and policies are generally guided by the ethical aspiration that people with impairments should have as much power and control over their lives as possible. The Americans with

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Disabilities Act, for example, requires that businesses and others make reasonable accommodations to people with disabilities. Even in patients who have lost decision-making capacity, respect for autonomy and human dignity generally entails honoring current preferences and accommodating or facilitating an incapacitated person's residual decision making to the fullest extent possible.

In the absence of an advance directive, when a person loses medical decision-making capacity as a result of cognitive impairment, family members have the legal authority to make decisions on the person's behalf, according to a hierarchy established by individual states. What right should family members have to decide whether their spouse, sibling, or parent may engage in consensual sex?

Moreover, what about the rights or even the dignity of the resident's spouse? Does a spouse have the right to be free from being a victim of adultery by a cognitively impaired husband or wife who lives in a nursing facility?

Dementia has many devastating effects not just on the patient, but also on his or her family members. The nature of every relationship with that person is changed. The social and emotional needs of loving family members may go unmet. Roles change. The spousal relationship may become more like a parent-child relationship, perhaps creating more and greater burdens.

Dignity and Privacy

What is dignity? We know it by both its presence and its absence. The essence of dignity is respect: respect for self or for another. The opposite of dignity is shame or scorn. We try to maintain the dignity of others by how we treat them. Should we also protect people from making choices that in an earlier life they would have been ashamed of? Do our actions respect the person as they are now, or do we try to preserve the image of that person as they used to be, even over their objections?

Given that people do change, that their values may change, and that they can change their minds in an instant, respect for people requires respect for the choices that they make now, all the while trying to protect them from harm.

Thus, autonomy and beneficence (the obligation to do good or protect from harm) are often in conflict. At present, American society places a greater emphasis on autonomy.

Nursing facility residents have a right to privacy as well as a right to freedom of movement within a facility. How can an individual's right to privacy be ensured, especially when he or she shares a room with someone else? The identical rights of two individuals may conflict, and thus do autonomy and justice.

As a purely practical matter, honoring the privacy rights of a nursing facility resident wishing to engage in consensual sex with a willing partner may require finding an appropriate place for the couple if neither has a private room. It may also require locking a door or otherwise ensuring that the couple is not disturbed.

Plan Ahead?

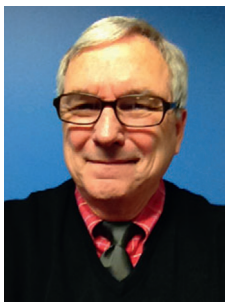
Perhaps issues related to sexuality could be addressed at the time of admission or as part of an advance directive. This might prevent future misunderstandings or other problems. On the other hand, asking about sex with future problems unknown will no doubt cause some residents to become embarrassed, offended, or both.

By and large, all of us want to do the right thing. We want to help our facility residents live as fully and as joyfully as possible. Likewise, acknowledging the vulnerability that comes from both impairments as well as circumstances, we want to protect residents from harm. The desire to do the right thing motivates and sustains us, even though, as this case illustrates, the right thing may not always be immediately obvious to everyone involved.

Dr. Evans is a full-time long-term care physician in Charlottesville, Va., and medical director of two skilled nursing facilities. He is AMDA's president and serves on the Caring for the Ages Editorial Advisory Board. You can comment on this and other columns at www.caringfortheages.com, under "Views."

Caring for the Ages Welcomes New Advisers

Dr. Simonson



Dr. Stone

Dr. Nichols

Caring for the Ages welcomes William Simonson, PharmD, Dr. Dennis L. Stone, CMD, and Dr. Jeffrey Nichols, as members of its Editorial Advisory Board.

Dr. Simonson has specialized in senior medication issues for more than 35 years. He has more than 150 publications and is the author of two books.

He has a faculty appointment as senior research professor (pharmacy practice) at Oregon State University. He has served four terms on the United States Pharmacopeia Advisory Panel on Geriatrics.

Dr. Stone was the first medical director of On Lok Senior Services, the forerunner of today's PACE programs. He is currently the chief medical officer of Signature HealthCARE and of Integritas HealthCARE, a Louisville, Ky.–based nonphysician service providing transitional medical and psychiatric services in nursing, home, and outpatient venues.

He has been an advisor to the AMA's Relative Value Update Committee and CPT Committee for 15 years and is a past president of AMDA.

Dr. Nichols is medical director, Our Lady of Consolation and Good Samaritan Nursing Homes, Suffolk County, N.Y., senior vice president for clinical effectiveness of the Catholic Health Care System of Long Island. He joined the Editorial Advisory Board in 2012, after last year's AMDA annual meeting.

We thank our outgoing board members Dr. Jon Berg, CMD, Frederick L. Wendt, RPh, and Dr. Bonnie Wirfs, CMD, for their service.

Dementia Onset Steers Nursing Home Admissions

Patients in whom dementia symptoms appear before age 65 are cared for at home longer than are people whose symptoms develop later in life, according to results from Needs in Young Onset Dementia (NeedYD) Study in the Netherlands.

Christian Bakker of the Florence Mariahoeve Centre for Specialized Care in Early Onset Dementia in The Netherlands and his colleagues used baseline data on 215 people with early onset dementia and 119 people with symptoms starting after 65.

The researchers interviewed each person's primary caregiver about the year of onset and the nature of first symptoms. The team also assessed neuropsychiatric symptoms and dementia severity.

The time from onset of symptoms to institutionalization was more than twice as long for people with early onset dementia (9 years vs. 4 years). Apathy and caregiver competence were significant predictors, but neuropsychiatric symptoms were not.

These results emphasize the importance of timely diagnosis to begin appropriate care and additional support programs for caregivers, especially those caring for people with neuropsychiatric symptoms, the researchers said. They reported their findings in the April JAMDA.

—Jeffrey S. Eisenberg