MEDICAL ETHICS

By Elaine Healy, MD, FACP, CMD

Intimacy and Dementia in Long-Term Care: Time for a Revisit

Long-term care communities have become the site to address some of the most compelling ethical questions of our day, and resolving these dilemmas may be especially challenging when the individual involved has lost the capacity to participate in the process. Individuals with dementia who seek intimacy in LTC settings present a unique set of challenges — absent demonstrate consent, sexual activity places the residents, their loved ones, and those who professionally care for them in significant jeopardy.

Questions of rape and abuse may be raised, and staff may be accused of aiding and abetting crimes; conversely, the residents may be unjustly prevented from engaging in intimate relations at a time when so doing may be one of life’s only remaining pleasures. Family members, particularly nonresident spouses, may experience profound emotional distress when their loved one commences a sexual relationship, and their role in decision-making is not well established.

In addressing the issue of sexual consent in dementia, it seems natural to employ the end-of-life decision-making paradigm; however, consent to engage in sex is not a health care decision, and no legal route for surrogate decision-making exists.

The Ethics Committee of AMDA – The Society for Post-Acute and Long-Term Care Medicine has commenced a review of this subject. This essay summarizes past findings and shares a process for achieving situational resolution once sexual decisional capacity has been determined.

The Society’s white paper states that for sexual consent to be valid, the ability to comprehend the nature of a sexual act, assess its risks, and rationally process these factors with regard to established values and preferences must be present. In addition, the individual must be aware of who is initiating sexual contact, be able to indicate what level of sexual intimacy is comfortable, and, above all, be able to say no to and effectively resist unwanted sexual advances. The paper acknowledges that “communication with the family should respect the privacy and autonomy of the resident when sexual capacity is deemed present, while engaging the family when consent capacity is unclear or diminishing.” Noting that most LTC facilities do not have policies and procedures pertaining to this issue, the Society encourages facilities to involve family members in such policy development and to disclose these policies at the time of admission.

When we address the issue of sexual consent in dementia, it seems natural to employ the end-of-life decision-making paradigm. After all, legal pathways pertaining to such decisions are well established, focused on ensuring that the prior wishes and values of the now-incapacitated individual are carried out. However, although the activity may occur in a health care facility, consent to engage in sex is not a health care decision, and no legal route for surrogate decision-making exists. In addition, few individuals have created advance directives pertaining to sexual activity, and even when these are present their fittingness has come under question. People with dementia typically live for many years with their illness; accordingly, certain ethicists debate whether it is appropriate to uphold an individual’s prior wishes if that person’s current, day-to-day needs and behaviors are inconsistent with them. This is based on the contention that the neurocognitive disorder or injury has caused significant disruption of memory and related cognitive processes that individuals are no longer the same people but rather have become a new and different self, capable of developing novel values and manifesting them by virtue of their behavior. These ethicists believe that deference should be given to the new values being demonstrated rather than the prior ones; as a result, the issue of capacity to legally consent to sexual activity may be considered less important than the perceived benefits of a sexual encounter. A comparable perspective was acknowledged by the Society with respect to the issue of “Stopping Eating and Drinking by Advance Directives” (SED by AD). Increasingly, people are authoring documents instructing that they are not to be hand fed in the event that they can no longer feed themselves. In 2019, the Society issued a white paper on this topic which recommends against implementing such directives when the now-incapacitated resident appears desirous of eating, favoring the provision of “comfort feeding” instead. The Society noted that “the family, facility and provider must now determine to whom they feel obligated — to the then-self and their advance directives, or the current desires of the now-self.” Ultimately, the viewpoint of the latter became the basis for the organization’s opinion.

How can LTC facilities balance the rights of cognitively impaired residents to engage in sexual activity with those of nonresident spouses and family members who participate in their loved one’s care? Fortunately, the Hebrew Home for the Aged in Riverdale, NY, authored its first policy on this issue nearly a quarter of a century ago. As referenced in the Society’s white paper, Hebrew Home’s policy provides a tried-and-true blueprint for facilities needing to develop such policies. Intimacy is acknowledged to be as critical to the well-being of those with dementia as it is to cognitively intact individuals — perhaps more so because it may be one of the few remaining pleasures they can experience. When a nonresident spouse or family member objects to a developing sexual relationship, the nursing home’s care team will encourage them to accept it; if the objection persists, however, the facility will take steps to discourage the relationship, including moving the resident elsewhere in the facility. Hebrew Home’s CEO has stated that the facility has never had an adverse legal or regulatory outcome as a result of this approach, establishing a substantial precedent from which all can benefit.

The Society contends that “a shared decision-making model between family and facility when the resident is losing capacity may cultivate a healthier and more satisfying outcome for all involved,” and the time may be ripe for the organization to officially endorse a decisional paradigm that upholds the newly demonstrated preferences of the resident while simultaneously recognizing the effect of the sexual activity on the family and formally involving them in the process. Accordingly, the following is suggested for further consideration:

1. Does the individual appear to be willing to engage in sexual activity?
2. Has the absence of coercion or victimization been established?
3. Who else, besides the resident, would be affected by the resident’s sexual activity? How would they be impacted by this?
4. Can the residents understand the consequences and implications of their decision and meaningfully consider previously held values and goals? If so, they have functional competency to decide for themselves; if not, the decision must be made for them.
5. The nursing home’s care team, inclusive of family members, then decides whether the benefit of the intimate relationship outweighs the resident’s prior values as well as the interests of the others involved. If so, the relationship should be allowed to continue; if not, it should be curtailed.

The baby boomers are linked to the sexual revolution of the 1960s, and they questioned and unraveled centuries of tradition, ethics, and morals in a quest to ensphere their right to experience the full range of human intimacy. In addition, they are socially generous, historically advocating on behalf of the needs, rights, and concerns of others. Given their intrinsic open-mindedness and munificence, there is hope that they will find a way to continue to benefit from intimacy while simultaneously considering the feelings and values of those near and dear to them. The Society can assist in the process by an ongoing evaluation of this complex issue and the provision of specific guidelines by which the needs of all concerned may be accounted for and addressed.

Dr. Healy is the medical director at United Hebrew of New Rochelle and the vice president of the New York Medical Directors Association. She is also a member of the Society’s ethics, annual program, and infection advisory committees.