

ETHICS CASE

Ethics and Intimate Sexual Activity in Long-Term Care

Commentary by Eran Metzger, MD

Abstract

A case is presented in which the staff of a long-term care facility discovers that the husband of a resident with dementia is engaged in sexual activity with her. The case illustrates a dilemma for long-term care facilities that create a home-like environment with a goal of maximizing residents' autonomy while ensuring their safety. An approach to assessing capacity to consent to intimate sexual activity is described, followed by guidelines that nursing homes can implement to support residents who wish to engage in sexual activity. Recommendations are also offered for supporting long-term care staff and family members of residents who are interested in intimate sexual activity.

Case

As a second-year psychiatry resident, Dr. Brian is working in a long-term care facility during his geriatric psychiatry rotation. The facility is structured to accommodate residents' escalating needs with various levels of care, ranging from independent living to assisted living to nursing home. Dr. Brian is working with a geriatric psychiatrist, Dr. Anderson, whose main role in the long-term care facility is to provide psychiatric consultation.

One afternoon, Drs. Brian and Anderson receive a consultation request regarding Mrs. Shera, an 80-year-old woman living in the nursing home section who has dementia. When reviewing her record, Dr. Brian sees that she was admitted to the long-term care facility about six months ago, after living independently with her husband of 55 years. Over time, it became more difficult for him to manage some of her behavioral issues at home. For instance, when she would take walks through the woods near their house, she would get lost on the paths. Sometimes, the police were called to search for her and take her home. When Mr. Shera tried to limit her excursions, she would become severely irritable, yelling at him and ultimately swinging at him when he tried to keep her from leaving the house. These episodes would last about 5-10 minutes, at which point Mrs. Shera would shut down and then forget what had just happened.

In the nursing home, Mr. Shera visited her as much as he could and she was always happy to see him. Once, a nurse walked into Mrs. Shera's room and found her and her

husband in bed together with some of their clothes removed. After Mr. Shera left, the nurse returned to talk further with Mrs. Shera about what had happened. Mrs. Shera indicated that she loved her husband and that he was a good man, but she wasn't able to answer questions about whether she felt comfortable engaging sexually with him. Troubled that Mrs. Shera's illness compromises her decision-making capacity, the nurse discussed her concerns with Drs. Brian and Anderson. After talking with Mrs. Shera, the nurse and the two physicians still were not clear whether and how it was appropriate for Mr. Shera to engage sexually with Mrs. Shera. They wondered what to do.

Commentary

Mr. and Mrs. Shera's story illustrates only some of the many challenges posed to long-term care facilities (also known as nursing homes) by residents who are engaged in, desire to be engaged in, or do not desire to be engaged in intimate sexual activity. When these situations arise, the treatment team is often faced with issues of capacity and consent, [safety](#), and privacy. The staff could find itself in an ethical dilemma created by trying to both respect residents' autonomy and protect them from harm. The facility might also need to address the varied reactions of different members of the treatment team, as human sexuality is an intensely personal topic and can give rise to conflicting views and embarrassment. The last two decades have witnessed increased scholarly attention to intimate sexual activity in long-term care [1-5]. This is likely a by-product of the resident-centered care movement. What originally started as an effort by a coalition of organizations committed to improving quality of life for nursing home residents led to language in the 1987 Omnibus Budget Reconciliation Act [6] that for the first time mandated by statute that a sector of health care provide "person-centered care" [7]. The intent of this movement has been to make nursing homes feel more like homes and less like medical facilities to their residents by eliciting and supporting their personal preferences, respecting their autonomy, and making changes to the physical plant. The case of the Sheras and other similar cases invite the nursing home to clarify its response to the challenging topic of intimate sexual activity by implementing (1) effective communication approaches with residents and among staff members, (2) assessments of sexual decision-making capacity, and (3) measures that will ensure resident autonomy, safety, and dignity.

Ethical Dilemmas Facing Nursing Homes

While trying to accommodate the individual preferences of their residents, nursing homes must also adhere to federal and state regulations created to ensure safety, comfort, and standardization of care. In some areas of care, regulations leave little room for interpretation. For example, residents who receive medications may not take them on their own volition but must have them ordered by the nursing home's medical clinician, dispensed by a nurse, and administered within a window of the prescribed time [8]. In other areas of care, nursing homes have more discretion—for example, by allowing an individual resident to choose when she will eat her meals and what clothes she will wear.

Absent from nursing home regulations are guidelines on how to assess and accommodate residents' preferences for intimate sexual activity. Federal government regulations instruct nursing homes that they "must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality" [9]. However, such mandates fall far short of providing guidance on how to respond to cases such as that of Mr. and Mrs. Shera and how to determine when intimate sexual activity might enhance or compromise dignity. In the absence of regulatory directives on intimate sexual activity, few facilities have devised their own [5]. Rather, there is a tendency for facilities to fall back on an approach that does not require the additional effort needed to discern residents' preferences in this area and does not challenge the comfort of the staff. This default position, however, runs the risk of compromising residents' quality of life and further impinging on their freedoms within an institutional setting.

Assessing the Capacity to Consent to Sexual Activity

In the Shera case, the team consults psychiatry because of uncertainty about Mrs. Shera's ability to consent to intimate sexual activity. That the psychiatrists, after interviewing Mrs. Shera, should likewise be uncertain should not come as a surprise. While Appelbaum [10] and others [11] have provided clinicians guidance on the assessment of medical decision-making capacity, there is a comparative dearth of information on assessment of capacity to consent to intimate sexual activity [12, 13]. The former focuses on the ability to accept or refuse an administered treatment, based on an appreciation of one's situation and the risks and possible benefits associated with treatment and nontreatment. In contrast to a medical procedure, sexual activity is considered in healthy and autonomous persons to be the expression of innate drives and an important determiner of well-being. In assessing medical decision-making capacity, the medical clinician *defines* the nature of the proposed intervention and who will perform it. In assessing capacity to consent to sexual activity, the clinician must *acquire* knowledge of the nature of the activity and the relationship of the participants. Clearly, a different approach is required for determining sexual decision-making capacity than that for determining medical decision-making capacity.

Lichtenberg and Strzepiek have described an approach used in a dementia nursing home unit to assess residents' capacity to consent to intimate sexual activity [14]. Key components of their assessment include determination of residents': (1) awareness of with whom they are having sexual contact and what that person's relationship is to them, (2) ability to articulate the type(s) of intimate sexual activity with which they are comfortable, (3) consistency of behavior with respect to their previously expressed beliefs and preferences, (4) ability to decline unwanted sexual activity, and (5) ability to articulate what their reaction will be if the sexual activity ends. The authors describe a two-step process whereby the multidisciplinary team, after completing the above

assessment, observes residents in their milieu in order to determine if their behavior is consistent with their interview responses.

An emerging literature on sexual capacity in persons with intellectual disability also provides some guidance. Writing about this population, Lyden [15] proposes that assessment of sexual consent capacity address the domains of rationality (“the ability to critically evaluate, to weigh the pros and cons, and to make a knowledgeable decision” [16]), sexual knowledge (“the specific sexual behaviors in question” and “the choice to accept or reject the sexual behaviors in question” [17]), and voluntariness (“aware[ness] that he/she has a choice to perform, or avoid, prospective sexual conduct” [18]). He also recommends that the assessment be performed by someone with whom the person is likely to feel comfortable, ideally someone of the same gender.

Just as the standard for determining medical decision-making capacity is adjusted depending on the nature of the risk of the proposed treatment [19], so, too, the standard for sexual consent capacity might be influenced by the nature of the sexual activity in question. Looking at opposite poles of the continuum, a lower standard of capacity would be applied to assess Mrs. Shera’s capacity to consent to kissing her husband (whom she “is always happy to see”) than would be applied to, for example, her consent to engage in sexual penetration.

Ideally, the clinician could enlist Mr. Shera’s assistance in the assessment. Areas to cover in an interview with Mr. Shera would include the nature of the intimate sexual activity in which he wishes to engage and to what extent this activity is consistent with their prior sexual activity. While a formal neurocognitive examination of Mr. Shera, who is not under the care of the team, would be inappropriate, observing for signs of cognitive impairment would provide additional data that would help the evaluator in her formulation. Can Mr. Shera, for example, articulate awareness and sensitivity to the possibility that his wife’s interest in intimate sexual activity might vary from day to day? Can he articulate how he will assure his wife’s physical safety during sexual activity? Is Mr. Shera aware of Mrs. Shera’s privacy needs? Concerns in any of these areas might prompt the team, with Mr. Shera’s permission, to seek ancillary information on Mr. Shera’s condition from one of the Shera’s children, if they have any.

Just as no medical or psychiatric diagnosis automatically confers incapacity for medical decision making, so, too, should clinicians refrain from inferring that a diagnosis of dementia is *prima facie* evidence of lack of sexual consent capacity. As one author has written, in reference to sexuality and Alzheimer’s disease, “As they say, when you have seen one case, you have only seen one case” [20]. There is increased acceptance in medical ethics that capacity is decision-specific [21]. Inability to make a decision about medical treatment or to manage finances should not be assumed to denote sexual consent incapacity.

Surrogate Decision Makers

The federal 1990 Patient Self-Determination Act increased dramatically the proportion of nursing home residents for whom a [surrogate](#) is identified to make medical decisions if the resident loses medical decision-making capacity [22]. While it might be the surrogate decision maker's responsibility to render a decision about a resident's sexual activity if he or she lacks capacity, this does not obviate the need for a careful capacity assessment that would help guide the surrogate decision maker in arriving at this decision. What if, as could well be the case with the Sheras, the surrogate decision maker is directly involved in the intimate sexual activity in question? Similar situations in which there is a potential conflict of interest for the surrogate decision maker faced with a *medical* decision occur as well. For example, the decision to withdraw medical treatment, in accordance with a resident's advance directives, might be resisted by the surrogate decision maker spouse who wishes to keep his partner alive as long as possible. Alternatively, the decision to embark on a costly treatment regimen recommended for the incapacitated resident could be resisted by the surrogate for whom it might have negative financial consequences. In each of these situations, the clinician has the important role of educating the surrogate on his duty to make decisions in accordance with the substituted judgment standard [23]. When there is concern that the surrogate is unable to do this, the team might need to petition the court for an alternate surrogate.

Working with a family surrogate decision maker—whether it is a spouse, an adult child, or a sibling—to address sexual behavior requires sensitivity to the possibility that the family member will be uncomfortable with the topic [3]. Of family work, one can also say that, "When you have seen one family, you have seen one family." Family members come to this topic with a wide range of backgrounds and comfort levels in discussing intimate sexual activity and, specifically, sexual activity of a relative. The clinician is well advised to give consideration before a family meeting to how a family member's personal, generational, and cultural background can influence the conversation. Some nursing homes have prepared printed educational material for families [4]. Starting the conversation by acknowledging the sensitive nature of the topic can be helpful in mitigating discomfort from the start. Family reactions have run the gamut from acceptance and encouragement of an activity that provides pleasure at the end of life to anger and threats to transfer the resident to another facility or take legal action against the nursing home [3, 5]. The staff member who discusses the issue with the family should also be aware of her own apprehension about distressing the family.

Family members are not the only ones who might experience discomfort over the topic. Nursing home staff members' personal attitudes about intimate sexual activity are similarly shaped by a wide range of individual, cultural, and religious influences, resulting in a similarly wide range of sensitivity to and acceptance of this issue. There is evidence that staff attitudes, too often a deterrent to resident sexual activity in the past, have

evolved in this area [3, 24]. The case of the Sheras involves heterosexual activity by a married couple. A case involving support of less “traditional” sexual activity such as nonheterosexual activity or infidelity is more likely to generate unease among some members of the treatment team [5]. In order for the team to provide consistent implementation of a plan, it is crucial that all members be provided a forum to express their concerns [4]. Allowing a team member who opposes the plan to opt out of caring for the resident might well be preferable to the detrimental effects on team morale caused by a disgruntled clinical caregiver.

Safety

Safety considerations affect not only the decision of whether to permit sexual activity but also, if it is to be permitted, how it can take place with minimum likelihood of harm. Here again, there is no substitute for frank discussion with the involved parties about the nature of the sexual activity involved and the physical and other risks associated with it. Such risks could include risks of falling, infection, and a cardiovascular event [25]. Negotiations might result in an arrangement that strikes a necessary balance between privacy and safety that entails, for example, a staff member periodically checking on the well-being of a resident during sexual activity. Recall that the Shera case comes to the attention of the treatment team after “a nurse walked into Mrs. Shera’s room and found her and her husband in bed together with some of their clothes removed.” Staff members should be coached on how to protect the privacy and dignity of residents engaged in sanctioned sexual activity. Approaches have ranged from the use of “Do Not Disturb” signage to providing a separate room for privacy when a resident does not have a private bedroom [4, 5, 14].

Towards a Resident-Centered Approach to Sexual Intimacy in Long-Term Care

The story of the Sheras will be familiar to clinicians who practice in the long-term care setting and is only one of many scenarios of sexual intimacy that the nursing home staff might confront. In keeping with the ongoing effort to create senior care environments that are respectful of patient autonomy and preferences, long-term care facilities are encouraged to include plans on how to accommodate sexual intimacy. Forrow and colleagues have advanced the concept of preventive ethics, whereby a medical institution engages in activities that can serve to decrease the likelihood of cases evolving into ethical conflicts [26]. Such activities include an emphasis on communicating early about potential conflicts and taking the time to reflect on what institutional factors might give rise to trouble down the road. Nursing homes can implement a number of strategies to help improve their readiness to address an instance of resident intimate sexual activity. Table 1 highlights some central action steps to help a facility prepare in this manner.

Table 1. Action steps for accommodating intimate sexual activity in long-term care [4, 5]

Preparation
Determine statutes and case law on sexual consent for your state. Draft guidelines for your institution’s management of resident sexual activity. Establish resources to support resident sexual activity: <ul style="list-style-type: none">• resident sexuality consultation team (analogous to palliative or wound care, infection control)• “intimacy room” for residents who do not have private rooms, appropriate signage• educational materials for staff, families• aids (e.g., lubricants) Hold staff training sessions.
Management
Consult resident sexuality consultant. Conduct sexual consent capacity assessment. Construct individualized plan detailing approaches to maintain safety and privacy. Hold staff support meetings.
Problem-solving resources
Ethics committee consultation State Long-term Care Ombudsman’s Office

Summary

Human sexuality and expressions thereof are a sensitive and deeply personal area of human experience. While no amount of preparation can anticipate every possible scenario, the approaches described here are likely to improve clinicians’ confidence in responding to intimate sexual situations in a manner that is respectful and consistent with the long-term care facility’s mission of creating a safe and life-affirming home.

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Eran Metzger, MD, is an assistant professor of psychiatry at Harvard Medical School in Boston. He is also director of psychiatry at Hebrew SeniorLife and a member of the Department of Psychiatry at Beth Israel Deaconess Medical Center. His research and teaching interests include medical ethics in long-term care, collaborative care treatment of depression in primary care geriatrics, and the biological basis of delirium.

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