Ethics Corner: Cases from the Hebrew Rehabilitation Center for Aged—Sex in the Facility

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This article is the fourth of a 6-part JAMDA series devoted to medical ethics in the nursing home. In each issue, a case is presented from the Ethics Committee at the Hebrew Rehabilitation Center for Aged (HRCA) in Boston, Massachusetts. Following a description of the case and a discussion of the ethical issues that the case raises, Dr. Steven Levenson discusses the implications for medical directors.

CASE PRESENTATIONS

Case 1

The Ethics Committee was asked to consult on the case of Elizabeth O., a 75-year-old woman who had been admitted to the Hebrew Rehabilitation Center for Aged (HRCA) 6 months earlier because her Parkinson’s disease necessitated extensive assistance with activities of daily living. The day before the consultation request, a staff member entering Mrs. O.’s semi-private room observed her partially undressed, engaged in sexual activity with a male resident. The two residents appeared embarrassed by the discovery, and the male resident left the room. The consult was generated by concerns among staff members about Mrs. O.’s judgment and by uncertainty about whether Mrs. O.’s family should be informed about her activity.

Mrs. O. was born in New York City, completed high school and worked as a bookkeeper. She married, moved to Boston with her husband and raised two children. Her husband now lived with their son and visited Mrs. O. at HRCA regularly. Mrs. O.’s relationship with her husband had been strained at times, and they had been separated for a period many years ago. Mrs. O. had designated her husband to be her health care proxy at the time of admission to the HRCA.

The Ethics Committee consultants met with Mrs. O.’s treatment team. Staff members related that they had previously observed Mrs. O. spending time with the male resident but had not observed nor been aware of sexual intimacy. Staff members were worried how Mr. O. might react were he to learn that his wife was involved in an extramarital sexual relationship. They wondered whether Mrs. O.’s family members might hold the staff liable for not informing them and for not interceding.

The Ethics Committee consultants viewed the treatment team’s concerns as revolving around two key questions: (1) Does Mrs. O. have the capacity to consent to a sexual relationship with another resident? (2) What is the treatment team’s responsibility to inform her family about her sexual activity? The consultants believed that the first question could be answered only after Mrs. O. had been evaluated for competency in this area. The consultants recommended that the center’s psychiatrist evaluate Mrs. O. with this question in mind. They recommended that the evaluation include a cognitive exam and an assessment of Mrs. O.’s ability to express both what she wanted and what she did not want in the relationship. The consultants also recommended that the psychiatrist evaluate Mrs. O.’s insight into the nature of her relationship with her husband and how her behavior might affect it. The ethics consultants recommended that staff intervene to discontinue the sexual activity were the psychiatrist to determine that Mrs. O. lacked capacity in the areas described above. The consultants felt that Mrs. O.’s lack of capacity would increase the risk that she might become involved in sexual activity that was not consensual.

Regardless of Mrs. O.’s capacity in this area, the consultants did not believe the team had an obligation to inform her health care proxy (her husband). The consultants felt that for purposes of protecting the resident’s autonomy, the proxy’s role should be limited to assisting with medical decision-making if the resident were to lack capacity in this area.

In the event that Mrs. O. were found to have capacity to continue her relationship, the ethics consultants recommended that her caregivers assist her and her partner in maintaining privacy. The consultants felt that the team had an obligation to make accommodations for Mrs. O.’s sexuality...
as well as a responsibility to protect Mrs. O.'s roommate from unwanted contact with the activity.

The psychiatrist who evaluated Mrs. O. found no evidence that she lacked the capacity to engage in a consensual sexual relationship with her companion. He added that Mrs. O. was aware of the possible impact on her husband and that, while she derived pleasure from the current relationship, she was ambivalent about continuing it. The treatment team elected not to inform the resident's husband, and the resident and her companion ended their relationship not long after.

**Case 2**

Mrs. P. is an 85-year-old woman who had been admitted to the HRCA 9 months before the ethics consultation. She was admitted from home because her memory loss and decreased mobility from a recent hip fracture rendered her unable to manage alone. Before her admission to HRCA, Mrs. P. had attended the senior day program at HRCA. There, she had struck up a relationship with a male program attendee who continued to visit her after she was admitted. The male companion himself had some mild cognitive impairment. The staff on Mrs. P.'s floor consulted the Ethics Committee after they observed her male companion caressing her breasts in a common area on several occasions. The staff on Mrs. P.'s floor, while uncomfortable with Mrs. P.'s inattention to privacy, felt that Mrs. P. was capable of consenting to the relationship. However, Mrs. P.'s son, who was not her health care proxy, had learned of the episodes and insisted that the staff intervene to terminate the visits between the two. In a telephone call, the son threatened that he would report the HRCA to a Boston newspaper if the team did not act. Mrs. P.'s daughter, who was her health care proxy, did not seem troubled by the activity.

Mrs. P. was born in Poland and immigrated to the United States when she was 7. She married soon after graduating from high school and had a son and a daughter. Mrs. P.'s husband died 20 years ago. Mrs. P. underwent neuropsychological testing before her admission to HRCA. Her test results were consistent with mild to moderate impairment from a vascular dementia. Mrs. P. had also been treated for depression before admission and continued to take antidepressant medication.

As in the case of Mrs. O., the Ethics Committee consultants for Mrs. P.'s case recommended an assessment of Mrs. P.'s cognition, her ability to consent to sexual activity, and her ability to decline unwanted activity. The consultants did not think that Mrs. P.'s inattention to privacy constituted evidence that she was incapable of expressing a preference regarding a relationship. The consultants further proposed that, if the competency assessment were to support Mrs. P. in continuing the relationship, Mrs. P.'s caregivers would have a responsibility to safeguard her dignity. Again, this would mean providing a private space for Mrs. P. and her partner. Finally, since Mrs. P.'s next of kin were already aware of her relationship, the ethics consultants recommended a family meeting so that the team could explain the rationale behind its decisions. The consultants recommended that the team educate the family about the notion of decision-specific competency, and provide reassurance that the team would continue to work to ensure Mrs. P.'s safety and dignity.

A psychiatrist evaluated Mrs. P. and found that, though she had some memory problems consistent with a vascular dementia, her judgment was intact. The psychiatrist reported that Mrs. P.'s relationship appeared to be a source of significant pleasure in her life and felt that "it would be a shame to take this away from her." The psychiatrist offered to meet with Mrs. P.'s family, and during this meeting the son became more accepting of both his mother's relationship and the team's approach. The psychiatrist met separately with the team to strategize on how the team could better protect Mrs. P.'s privacy. The team agreed to offer the couple use of the floor's treatment room, which was otherwise in use only during physician rounds.

**CASE DISCUSSION**

Only relatively recently has the topic of sexual activity in the elderly, let alone sexual activity in the institutionalized elderly, received attention in the geriatrics literature. Recent studies have confirmed that a significant minority of nursing home residents maintain an interest in sexual activity but face major obstacles to acting on these interests.1 Among the barriers to sexual expression described by nursing home residents are lack of privacy, lack of a willing partner, and attitudes of the staff and physicians.2 In response, some nursing homes have initiated programs to increase staff sensitivity to resident sexuality. Recently, New York State distributed to all of its nursing homes a training video on resident sexual expression produced by the Hebrew Home for the Aged in Riverdale.3 The cases of Mrs. O. and Mrs. P. illustrate the challenges faced in providing for the healthy expression of sexuality while protecting vulnerable residents. These challenges are increased when the cognition of one or both of the participants is impaired.

**Sex and Competency**

In both cases, the Ethics Committee's first recommendation was that the residents about whom the staff members were concerned be evaluated for capacity to consent to sexual activity with another resident. For several reasons, such an assessment can be difficult. Guidelines for determining this kind of "sexual competency" in the elderly have not been devised. Berger argues: "A decision to be responsibly sexually active requires consideration for personal health, the partner's health, for interpersonal relationships, and for other persons' concerns. An informed decision to be sexually active requires capacity for insight, judgment, and to understand consequences of one's actions."4

However, efforts to create guidelines for determining sexual competency run the risk of holding nursing home residents to a higher standard than is applied to younger sexually active members of society. In the cases of Mrs. O. and Mrs. P., the Ethics Committee recommended that the competency exam focus on the resident's insight into the nature of the activity in which she was engaged, whether there was any evidence that the sexual activity was involuntary or coerced, and whether the resident was aware of the possible consequences of the behavior.
The clinician seeking to assess sexual relationship competency faces additional potential obstacles. A physician’s request to have a frank and explicit discussion of sexual preferences may be intimidating to a resident not used to sharing such personal information. How is the examiner to interpret a resident’s reluctance or outright refusal to have such a discussion? Is the mildly demented resident’s lack of recall for a particular episode an indication of a memory problem or modesty? While there are no simple answers to these questions, the evaluator of sexual competency may be guided by principles which apply to other competency assessments.

As has been discussed in previous Ethics Corner articles, autonomy is a central principle of American bioethics, and nursing home residents deserve to be protected from threats against personal autonomy posed by the long-term care setting. In the case of sexuality, caregivers may feel pressured to compromise a resident’s autonomy because the activity in question is one that makes others (staff, family) uncomfortable. Activities that would be considered acceptable “in the privacy of one’s own home” should not necessarily be denied because many share the home.

As with other areas of competency, a particular medical diagnosis does not automatically render a person incompetent. Whether a person with dementia has the capacity to consent to sexual activity must be determined by a clinical assessment of how the dementia impinges on the abilities required to make decisions in this area. An individual who must defer to her health care proxy a decision about a particular medical treatment may yet be able to make valid decisions about sexual relationships.

Sex and Dementia

The challenge of determining the appropriateness of sexual activity in a patient with dementia is further complicated by the fact that sexual disinhibition can be a symptom of dementia, albeit in a minority of patients. On the other hand, increased sexual activity may be a legitimate reaction to increased freedom from family constraints or a reevaluation of priorities. How does one determine the respective contributions of “organic disinhibition” and social liberation to observed sexual activity?

Post argues the importance of obtaining a person’s life story and judging current behavior against previously held values. He maintains that even persons with advanced dementia are capable of moments of insight and are thus vulnerable to feelings of shame or guilt if allowed to violate their values. He acknowledges a personal bias in this area, however. “I personally would wish to have the integrity of my life journey protected against the waywardness created by dementia, although utilitarians, who are locked in the pure present, might disagree.” One might, as Howe proposes, encourage individuals to discuss advance sexual directives with their families. Given the modest rates at which individuals discuss with family advance directives for end-of-life-care, it seems likely that participation in an advance sexual directives initiative would be quite low.

Sex and Policy

While sexual advance directives may not be realistic, advance planning by nursing homes in the form of policies and procedures can assist treatment teams to address sex in the facility. A nursing home should, for example, articulate a clear position on the matter of informing family about a resident’s sexual activity. The health care proxy has authority to make medical decisions if the resident lacks capacity; by making a substitute decision, the proxy protects the patient’s autonomy.

It is hard to conceive how informing a health care proxy about a resident’s intimacy with another resident would safeguard autonomy, and easier to argue the converse. Treatment teams do inform families of important developments, quite apart from the health care proxy role and irrespective of a resident’s competency. It is arguable that a family needs to know with whom a resident is associating and how, and providing such information again further compromises the resident’s autonomy and sense of control.

Policy and procedures on resident sexuality should include provisions for staff education. Physicians should be reminded that overlooking the sexual history is not justifiable simply because the resident is being admitted to a nursing home. When a resident expresses an interest in sexual activity, a resource should be available to make the resident aware of the availability of aids such as educational material and lubricants. There should be provisions for training to improve nursing staff members’ comfort with dealing with sexual issues, their skills for communicating about sex, and their sensitivity to resident privacy.

As in the case of Mrs. P., situations may arise in which a resident’s family member becomes aware of the resident’s sexual activity. The treatment team would be wise to anticipate the family member’s discomfort in dealing with this issue. For many, talking about sexuality can be difficult. Such discomfort could result, for example, in a family’s hurried request to forbid all future sexual activity. The treatment team can help prevent such occurrences by conveying its willingness to discuss these matters openly with the family. In this way, the family may gain acceptance of the nursing home staff’s goals of preserving a resident’s autonomy while ensuring safety and protecting dignity.

REFERENCES