Sexuality in Long-Term Care: Ethics and Action

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author: Michael Gordon, MD, MSc, FRCP, CRCP (Edin), and Marcia Sokolowski, BA, Dip. CS, MA

Introduction

Given the "home-like" atmosphere that long-term care facilities are often committed to creating, plus the ideological stance that provision of a rich and meaningful experience entails addressing sexual desires and needs, an array of challenging ethical issues abound.

This article details a specific case scenario involving two residents experiencing different degrees of dementia, wishing to engage in a romantic and possibly sexual relationship. While not exhaustive, a number of ethical issues are raised, specific to the context of long-term care.

Ethical concerns regarding expression of autonomy, preservation of dignity, competence related to informed consent, privacy, and protection from harm are identified. While some aspects of the ethical deliberation processes are made more transparent than others, the authors underscore the importance of applying a sensitive and reflective approach in dealing with residents, staff, and families in trying to balance dignity, privacy, and protection needs.

Case Study

It was an initiative of a regional long-term care association to develop an ethics committee and program to serve their long-term care facilities. As chair of a long-established ethics committee in a large academic long-term care facility, one author (Michael Gordon) agreed to help develop their program and provide guidance in ethics-related challenges.

The newly formed ethics committee was eager to present the case. A senior nurse on the committee presented the following: "We have two residents who have developed an emotional bond and what now appears to be a physical and possibly sexual relationship. We need some help in dealing with the ethical implications and consequences of their actions, as well as with the response of staff and the two residents’ respective families."

She continued, "They are a widow and widower, both living at the facility, he for 5 months, she for a year. Mrs. X is moderately cognitively impaired but still able to do her activities of daily living (ADLs), is active, and participates in many of the social activities. Mr. Y is minimally cognitively impaired but required long-term care because of a previous stroke (which left him with a nondominant mild hemiparesis), diabetes mellitus requiring insulin, and severe social isolation. He was living on his own with no local family in the vicinity to assist him, and he was functionally declining prior to his move. He has flourished in his new environment and participates in the unit’s many social activities."

The social worker added, "Under normal circumstances Mr. Y probably could still have managed in the community with assistance, but because this was not possible and he was deteriorating despite available community-based services, he was admitted to the nursing home. He started 'courting' his 'girlfriend' during the afternoon social activities, and she clearly responded to his overtures. At first all the staff just thought it was a 'nice social relationship.' Even Mrs. X’s two children who each visited at least once a week noted that their mother had perked up from the attention that Mr. Y provided to her. They thought it was 'cute' that the two seemed so close." The nurse continued. "Then the staff found them hugging and kissing one day in the sunroom when no one was there and noted that when they sat together they were always holding hands and expressing physical attraction. It was when they found Mr. Y in Mrs. X’s room with his arms around her in bed that they became concerned. Even though they were dressed at the time, the staff realized that it was likely only a matter of time that their relationship might become overtly sexual."

Families’ Responses

The team decided that it was important that the families of the two residents be informed of what was going on so that there would be no surprises. They wondered whether they had any responsibility or duty to promote or discourage an outright sexual relationship. They were concerned about the possibility that the young couple might become very protective of their mother and feel that she was being taken advantage of considering her impaired cognition. The team also speculated that the adult children might perceive their mother’s actions as being disloyal to their late father (to whom their mother had been married for almost 60 years and who had died five years previously).1 Perhaps they themselves might feel a party to the disloyalty if they did not object to it. The staff was less worried about Mr. Y’s two sons and one daughter, who they believed would support their father’s new friendship and intimacy. They had indicated that their father was a very loving person who complained about his loneliness after his wife died. Lastly, the staff discussed how they would work with the couple to assure their privacy. Mrs. X had a private room whereas Mr. Y shared a room. Both shared the unit with 30 other residents.

Ethical Implications

The committee focused on a number of issues with ethical implications and identified potential preconceptions guiding the different views.2 One issue was whether or not there was a commitment to try and provide a home-like atmosphere to the long-term facility. Another was how to promote the well being of the residents by honoring their sense of dignity and independence, while balancing safety and...
With regard to the ethical principle of autonomy, the team questioned whether Mrs. X was sufficiently cognitively intact to consent to a sexual relationship given her moderate degree of dementia. There is debate about how much rigor should be applied to the standards used to assess the legal concept of capacity, and it pertains to sexual activity. Generally speaking, a higher degree of rigor is applied in situations where the risks are potentially great. The concern is less about someone’s ability to fully understand and appreciate the risks and consequences of their decisions if the potential for harm is minimal. If there is greater potential harm, as where someone was likely to be exploited or coerced, the standard for capacity might be higher. In Mrs. X’s case, the team believed that she was capable to consent to sexual activity, in the absence of contrary evidence. She was expressing her autonomy by deciding whom she wanted to be with, and there was nothing to suggest that she was being coerced or exploited by Mr. Y. Everyone agreed that she had in fact blossomed as their relationship developed.1,4

No one questioned whether Mr. Y had the capacity to enter such a relationship, nor was there any suggestion of consent being achieved through the use of force or coercion. It was acknowledged that consent could become ambiguous, especially when one partner is more cognitively impaired than the other, and in situations where one might become disoriented or confused during sexual activity.1,3,5,6

The Role of Family as Surrogates

Another ethical challenge focused on the “how and when” (if at all) of involving the residents’ families, in terms of alerting them to the relationship, including them in team discussions, and having them potentially involved in decision making. It was felt that it was appropriate to notify the families, but issues of privacy were acknowledged and discussed in terms of their balance with safety and protection concerns. There was concern expressed by some that it was unethical to alert the families in situations where there was little or no potential harm. Others felt that to exclude families would run the risk of undermining support and trust from family members. Some argued that sexuality was not a “treatment” and thus not necessary to promote or oppose, unless coercion or exploitation or other harm was suspected or known.1,3,5,6

In this case, as expected, Mrs. X’s children were opposed to such a relationship and wanted the staff to prevent it from developing further. As their mother’s legal surrogate, they felt it was their duty to act on her behalf to “protect” their mother.1,5,6 It was not clear if they understood their legally defined roles and responsibilities as surrogates: whenever possible, to reflect on their mother’s wishes; when not possible, to act in her “best interest” rather than as they felt she should or in a way that satisfied their needs and values.

Some team members believed that a person with moderate dementia, as is the case with Mrs. X, was a “different person” than she was prior to the progress of her dementia. If so, it logically followed that surrogate decision makers ought to decide based on the “current” person’s wishes or best interests, not the person they knew pre-dementia. Others felt that the duty of the surrogate should be to act on the wishes/values/beliefs of the resident before the onset of dementia. In the case of Mrs. X, the children believed that their mother displayed behaviors and attitudes that reflected a continuation of her foundational values and beliefs expressed throughout her life. They rejected the bifurcation between “then and now” persons, and argued that it would go against her core values and beliefs to act in ways she would other than to be a wife and a mother. They wanted to protect her from experiences of shame and guilt she might feel later. Given the disparity between the degree of dementia between their mother and her suitor, they wanted to protect her from potential exploitation. While the staff empathized with her children, they did not feel that the daughters’ wishes should or could override those of their mother. They did consider how the organization could better serve residents and families through policies that addressed issues related to sexuality, privacy, and involvement of families.1,3,5,6

Ethics Committee Opinion and Action

There was consensus on the committee, which included community members, that the couple should be able to manifest and demonstrate their mutual sexual autonomy. That Mrs. X suffered from moderate dementia did not necessarily imply that she did not have the capacity to make decisions regarding sexual activity with another resident. As for her children, the social worker agreed that it was necessary to help the children understand that they would have to find a way to support their mother’s sexually related decisional ability. They would require support to separate their personal wishes from their mother’s. This was going to be a major challenge and would probably require time and effort. It was considered worthwhile to have the children of the couple meet together in order to help them develop supportive roles in respecting their parents’ wishes.1,3,5,6

The Challenge of Privacy

The last challenge reflecting the ethical principle of justice was how to respect and promote the couple’s privacy while not unfairly putting other residents or staff members in a potentially embarrassing situation. The use of Mrs. X’s private room for rendezvous was considered potentially acceptable, but how could one be sure that no one would inadvertently enter during what could be an intimate moment? The doors on the units did not have locks on them, but a lock could be installed on their door. That raised the question of whether all the rooms should be lockable and discussion of the issue was not addressed. The idea of developing a private room was considered by some to be potentially acceptable, but how could one be sure that no one would inadvertently enter during what could be an intimate moment? The doors on the units did not have locks on them, but a lock could be installed on their door. 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Conclusion

The ethical principle of autonomy for decision making in cognitively impaired individuals in long-term care usually focuses on end-of-life issues such as feeding and clinical care issues, for which surrogates often play a significant role. Issues related to sexuality will continue to take on increasing importance as more individuals have the desire and capacity to experience emotional and sexual attachment. It is already much more acceptable for older persons to demonstrate overt sexuality in the general community, and this will likely carry over into the long-term care sector. We have long recognized that diagnosis of dementia does not in itself determine in which domains a person may be capable of making decisions. The idea of “global impairment” other than during the very late stages of dementia has been replaced by capacity in defined domains with choices such as those related to preferred and important relationships being well preserved until the dementia is well advanced.3,4 As health care professionals working in long-term care, we have an obligation to respectfully acknowledge our residents’ needs to form close and loving relationships, including the desire for sexual intimacy. We may find ourselves confronting an array of ethical challenges. The ethical principle of autonomy as well respect for and commitment to, dignity and protection from harm (ethical principle of nonmaleficence) are important, and they need to be weighed and balanced. It is also very
important to consider cultural, religious and spiritual meanings that inform the values and beliefs held by residents and families.\textsuperscript{1,3,8}

It can be challenging to separate personal and moral sensibilities when they conflict with those of others.\textsuperscript{2,4,9} An additional challenge occurs when we are attempting to critically examine long-standing myths surrounding older persons’ abilities to make decisions, including those related to sexuality. Evidence of dementia should not necessarily preclude a decision to offer support to residents wishing to express their sexuality within a long-term facility. The development of respectful supportive structures that allow for the creation of meaningful policy development and implementation will be indicative of a progressive organization. To respect and support the autonomy and dignity of long-term care residents, in concert with a safe and nurturing environment, is a laudable and achievable goal.

Please submit manuscripts on ethical issues in long-term care to Fred Feinsod, MD, MPH, CMD, Department Editor, at Feinsod@fmmh.com.

References:
5. No authors listed. What do you identify as problems with sexuality for patients, families and staff in nursing homes or long-term care facilities? What type of interventions have you found useful? J Gerontol Nurs 1997;23:52-55.