

# Sex, Dementia and the Nursing Home: Ethical Issues for Reflection

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## ABSTRACT

Elderly persons diagnosed with dementia sometimes engage in sexual relationships with other residents who, like themselves, live in nursing homes. In general, many Canadian long-term care facility caregivers and family members find this to be morally distressing. This article involves an anonymized case that is a composite of several real cases. As an ethicist working at a long-term geriatric care facility, I am commonly consulted about dementia and sexuality. The issues are complex, requiring reflective team deliberation and appropriate stakeholder engagement. This article's focus is the ethical concepts of autonomy and vulnerabilities or risks; more specifically, the challenges of balancing individual autonomy against professional and organizational duties of protection.

**Key Words:** sexuality; dementia; relational autonomy; nursing homes; ethics

## The Setting

The context is an Ontario long-term residential care facility serving several hundred geriatric residents, with the majority being diagnosed with Alzheimer's Disease, whether at an early, mid or later stage of progression. The most common form of dementia in older people is the Alzheimer's type where characteristically there is declining function amongst a number of intellectual abilities (Fellows, 1998). The particular facility is committed to creating a "home-like" atmosphere and to upholding the rights of the residents as set out in the Ontario Long-Term Care Homes Act.

Particular rights worthy of mention for the purpose of this article include the right "to be afforded privacy in caring for his or her personal needs," the right "to receive visitors of his or her choice and to consult in private with any person without interference," the right "to form friendships, to enjoy relationships," and the right "to pursue social interests" (Ontario Long-Term Homes Act, 2007)

## The Case of John and Mary

John is an 83 year-old widower with early onset of Alzheimer's Disease. He has been in this long-term care setting for two years, having arrived shortly after the death of his wife. John has three adult children who visit weekly and are very involved in their father's life. While John has some memory loss and associated distress, he continues to present in much the same way as his family members and friends remember him to have been in the past – very outgoing, a lover of music and dance, eager to socialize and generally having an upbeat temperament. Apart from his early stage of dementia, John's physical health is very good.

Mary is 79 years old, exhibiting signs of moderate or mid stage Alzheimer's Disease. She tends to be quite forgetful and often does not recognize her family members, including her husband, Joe. Her demeanour is pleasant and she often smiles and laughs. She has been a resident in the same care facility as John for almost one year. She and her husband have been married for fifty-five years, and they have two adult daughters who visit almost daily. Joe, who lives independently in the matrimonial home, often accompanies them on their visits to their mother. He remains a staunch supporter of his wife, and despite his own increasing physical ailments, never misses an opportunity to spend time with his wife and meet with the medical team to advocate for what he determines is best for his wife.

Six months ago John and Mary started spending time together, often seated at the same dining table for meals and attending recreational activities in each other's company. Usually it was Mary who would seek out John for companionship; the latter nonetheless appearing delighted she had done so.

Very recently they were found by the attending nurse in Mary's bed, lying naked and fondling each other. The nurse was horrified and insisted that John return to his own room and that they "no longer have sex or any contact together again!" The nurse called for a team meeting and a number of concerns were identified either by her or most of her colleagues. The team generally believed that given Mary's current state of dementia, she could not have consented to sex with John. They believed that their first duty would be to protect Mary from what was believed to be exploitation by John. Clearly, they asserted, John took advantage of Mary. Additionally

they worried that Mary would be viewed by her children and husband as being an adulteress, even though they (the team) attributed full responsibility for the sexual encounter to John.

The majority of team members recommended that both families ought to be contacted immediately and briefed about what had happened and that steps ought to be taken to separate John and Mary to avoid any such future re-occurrences. The team social worker, however, raised her concern that team members were responding too quickly, too emotionally, and likely inappropriately projecting their own personal values. She felt that the residents' autonomy, more specifically their right to self-govern and to make their own choices, was possibly being violated. Furthermore she worried that it might be a legal and/or moral breach of privacy to contact the families about Mary and John's sexual relationship. Nonetheless the team decided to contact the respective families to divulge the details in separate meetings with each of them.

## The Families' Reactions

All three of John's adult children felt very supportive of their father forming a new attachment with Mary, given how lonely he has been since the death of their mother. Furthermore they felt it was their father's "private business" how he conducted his personal life, and not something they had the right to meddle in, given he "knows what he is doing." At the same time, they recognized that they might feel differently when he becomes more impaired, as his dementia progresses, given he will likely not be as responsible for his actions as he currently is.

Mary's husband, Joe, was shocked, felt deeply betrayed and blamed the staff for not keeping a "closer watch over her." He insisted she likely mistook John for himself and given that she was always a devoted, loving wife, she was now clearly acting "out of character." One of the two adult children agreed with her father and further worried that probably John was taking advantage of their mother. She felt that their mother would be "appalled" if she could really appreciate her own behaviour, and that the two should be separated permanently. However the other adult child wondered aloud if their mother was now living a different sort of life with different values that deserved to be honoured. She observed that her mother currently seemed much happier than she did before she developed dementia. She challenged her sister and father about why they kept referring back to the "old Mary" as if the "new Mary" needed some sort of protection, or should not get to "count as much" as the "old Mary" did.

## Ethical Issues and Discussion

There are a number of significantly relevant ethical issues worthy of exploration. Mainly I will discuss this case as it relates to concepts of autonomy and non-maleficence.

### *Principle of Autonomy*

There are many definitions of autonomy but most focus on the right to self-govern, to act on one's own choices, according to one's

beliefs and values. While Ontario's legal framework for consent and capacity recognizes that capacity can fluctuate with changes in personal circumstances, different jurisdictions may have different laws governing the right to make decisions autonomously, and there is potential for more confusion if the fluctuating nature of capacity is not legally recognized or supported in the care context. Unfortunately, my experience is that a significant number of care providers tend to construct autonomy as a dichotomy – one either has autonomy or one does not have autonomy.

This dichotomy is not helpful to healthcare providers or families or clients. Nor does it capture reality. In reality, people with dementia have *fluctuating* abilities to govern themselves in different contexts and to act according to the values and beliefs that matter for them. Autonomy is therefore not static, but rather is dynamic and flexible. While, generally speaking, one becomes less autonomous overall as dementia progresses, even in later stages vestiges of lifetime values and beliefs might be maintained. I suggest it is more helpful and realistic to conceive of autonomy as existing on a continuum. One can be *more* or *less* autonomous. I also suggest it is wrong to assume that because someone has dementia, he/she can no longer be autonomous (Fellows, 1998).

Particularly in mainstream North American cultures, concepts of autonomy and cognitive capacity are used interchangeably. This is because we tend to apply "hypercognitive" criteria to autonomy; that is, one needs to have a requisite intellectual level to be considered to have autonomy (Post, 2006; O'Neill, 1997). Additionally, competence or capacity is viewed largely as related to intelligence and decision-making abilities. It may be short-sighted to equate autonomy with capacity, and to understand capacity as being narrowly construed to mean only decision-making or intellectually able (Dodds, 2000). Instead, I suggest we conceive of autonomy as being more fully related to the expression of one's values and beliefs, linked to social, emotional, religious and spiritual realms of personal identity. Intellectual prowess should not be the defining trait of autonomy.

Persons with dementia can still be "valuers" – persons who retain an interest in certain values and beliefs that shape how they wish to live their lives, and possibly can still create new/different values for oneself (Jaworska, 1999). It seems to me that Mary and John likely demonstrate through their ongoing relationship and desire to seek out each other's company that they value friendship and intimacy, even though they may no longer be able to demonstrate other decision-making and cognitive skills to the same extent they were formerly able to or in the same way. If we conceptualize autonomy more broadly, separated from our usual medical/legal competence to consent criteria and appreciate what we and others observe as indicators of values and beliefs, then we include persons of dementia as members of a community of moral agents. And thus we view John and Mary more holistically as persons with physical, emotional, social and sexual interests, just like the rest of us.

Additionally, the concept of *relational* autonomy may be compelling and worthy of consideration when we deliberate ethical issues related to John and Mary's case, as well as to others (Sherwin, 2004). Traditionally, autonomy is understood in the context of the self in isolation; terms such as "self-made", "self-interested" and "self-related" come to mind. Relational autonomy challenges this paradigm. It does so by conceptualizing the self as necessarily

being a social self, influencing others and being influenced by others and developed in relation to others. It is interesting and helpful hopefully to also ponder the implications of the notion of a relational self for ethical issues related to dementia and sexuality. I believe an argument can be made for others having some moral obligation to try to understand the meaning of the behaviours being exhibited by the persons with dementia in order to capture the values and beliefs they are trying to express, to try to make sense of what they are saying about how they wish to live their current lives (Post, 2006). Other people can and should help them express their desired actions in appropriate ways. We ought to assist them in ways they require to be able to live more authentically, to acknowledge and support their desires for friendship and intimacy and for privacy. Given a moral communal context, the needs of others in relationship with persons with dementia ought to be considered as well, such as other residents, family members and staff.

### *The “Now” versus the “Then” Person*

There is a long-standing debate about whether we ought to privilege the values, beliefs, wishes of the person before dementia set in, the “then” person, or the “now” person in these sorts of matters (Dresser, 1995; Dworkin 1993). Sexuality policies tend to privilege the “then” person as the “authentic” person, and if the current person with dementia exhibits behaviours, values or wishes that do not cohere with their former ones, there is a tendency to devalue the present behaviour. Not uncommonly a resident’s family member will proclaim: “She is acting out of character” or “He would be so ashamed if he really knew what he was doing now!” Privileging the “then” person has to do with the belief that the moral agency of the person is responsible for a more or less unified life with consistent values and behaviours (Kuczewski, 1999). According to this line of thinking, deviations from usual or “normal” behaviours are viewed as pathological.

One of Mary’s daughters held this view and it is a logical extension of this belief that the “errant” behaviour be stopped. Based upon her belief, Mary’s daughter behaved rationally when she insisted that her mother and John be separated. However, if we challenge this view and allow that personhood is not fixed, that there are numerous ways for a person to live their lives and that values can authentically change, then Mary’s behaviour can be understood differently, perhaps as a healthy way to connect with others. Perhaps the relationship between Mary and John is an expression of their authentic selves, in the current context of living their lives with dementia. This position seems more closely aligned with the views of Mary’s other daughter.

Resolving this personhood debate is not within the intent of this paper, and certainly the debate about personhood continues, as it likely should. What is important to understand, however, is that care providers and family members are not a homogeneous group when it comes to beliefs about personhood, and that their views, whatever they may be, will strongly influence their own reactions to learning about residents with dementia being sexually involved with each other.

The following section which addresses the principles of non-maleficence (do no harm) reinforces an important moral restraint upon autonomy: while it is important to strongly advocate for

upholding of autonomy, this can only be accomplished to the extent that concerns or harms are mitigated or significantly decreased.

### *Principle of Non-Maleficence*

Undoubtedly it is very challenging to define harms and benefits, to measure them, and to appreciate the different experiences of them for all the stakeholders involved. Additionally it is difficult to ascertain when the harms (whatever they may be and according to whom) may override the benefits (whatever they may be and according to whom). Along with the duty to uphold autonomy, long-term care facilities also have an obligation, both legal and ethical, to protect vulnerable persons from harm of abuse and neglect (including their own potential harm of legal liability and reputation). There is potential conflict between incompatible legal duties to provide protection from abuse and neglect and to allow residents their right to form social relationships and meet with others in privacy. Regardless of the challenges inherent in defining, assessing and balancing harms and benefits, it is vital that institutional processes be put into place to attempt to do so with each specific case.

### *Potential Harms to Residents*

Residents with dementia are potentially at risk of more harm due to their increased vulnerability to being emotionally and sexually exploited as a result of cognitive impairment. However it is also potentially harmful to not acknowledge and support their rights to autonomy; that is, to live their lives as fully authentically as possible without suffering the harms of ageism and stigma attached to having a dementia diagnosis.

Undoubtedly there are potential harms for both John and Mary in relation to their involvement in a sexual relationship with each other. John may be viewed as a perpetrator and placing himself at risk of criminal charges in the face of concerns about Mary’s capacity to provide informed consent for sex with him. He stands to have his reputation tainted. Additionally John might be treated punitively by staff or other residents and/or socially isolated. As a result, he may suffer from depression, feelings of decreased worth and confusion. If staff continue separating him from Mary, he might suffer intense feelings of grief and abandonment. Negative feelings might give rise to acting out behaviours. He also may receive medications to curb his libido and face the risks associated accordingly. John may also withdraw from family members, friends and staff.

Mary may suffer the wrath of or loss of relationship with her husband and other family members who do not want her to be sexually involved with any residents. She may be shunned or punished in other ways by staff and/or residents who learn about her sexual trysts with John. Even if it is perceived that Mary has agreed to past sexual encounters with John, her dementia might render her forgetful during or afterward, leaving her vulnerable to experience sexual acts as exploitive or abusive in their nature. She might be prone to the effects of trauma, including depression, anxiety, hyper vigilance, and feelings of worthlessness. She might retaliate against John in a harmful way. Additionally Mary might lose trust in the staff’s ability to protect her. If separated from John, she might experience intense isolation and grief.

What is glaringly missing in this case so far is any attempts by the staff to try to understand from John and Mary's points of views separately what meanings the relationship holds for each of them, how free each feels he or she is to decline any romantic/sexual offerings or advances, what values are currently being held in high esteem by each of them and how able each is to identify for themselves what the risks, benefits and consequences are of having a relationship together. They may require help by staff or family members to better understand these important issues for themselves, along with a deeper grasp of their own desires and feelings.

When the team decided to separate John and Mary and contact their families, neither John nor Mary seemed to be showing signs of distress, of being victimized, or otherwise of being harmed by the relationship. However, it is premature to rule these out as possibilities. While not evident to others, there is a problem with knowing what really are the subjective experiences of Mary and John. Perhaps Mary seeks out John because her husband is less available to her than is John. As dementia progresses for each of them, their interests, desires, values and subjective experiences of their relationship together are subject to change as well. In the case of advance dementia, what on balance was deemed a benefit may, in a different context, be experienced as a harm. Coping mechanisms may change, interests and desires may alter radically, and one or both might wish to end the relationship but not feel empowered to do so. It is impossible to identify all harms, but these aforementioned ones are highly significant and the organization is morally obliged (and perhaps legally obliged) to stand in as the protector of harms, to the extent reasonable (the meaning of which remains debatable as well). However, the staff decision to disallow any further contact between John and Mary before undertaking a process to assess the likely harms and benefits was, in this author's opinion, at best premature, and at worst, morally abhorrent.

#### **Other Potential Harms**

As aforementioned, it would be remiss to not consider the potential harms facing organizations and family members when residents with dementia are engaged in sexual relationships. In this particular situation Mary's husband was understandably very distraught, feeling betrayed both by Mary as well as by the organization which he believed did nothing to prevent the relationship. One of Mary's daughters was also very hurt and angry, feeling a sense of allegiance to her father and worrying that her mother was being exploited. While John's family did not feel personally wronged by him, they certainly could suffer harm if, for example, a law suit was launched against their father. In the current situation, their father was being separated from Mary and it remains to be seen how well John will fare from an emotional/social point of view as a result. Clearly this is a family who cares very much for the well-being of their father and will likely suffer some type of emotional upset, degree yet unknown as well, if they witness any emotional grief on his part.

Of course there are potential harms that the organization could face, including law suits, a tarnished reputation, as well as breach of trust with residents, staff, families and the community at large. Unfortunately these harms could ensue even if there was no harm incurred by either Mary or John. Other stakeholders, such as family members who are not in support of the sexual relationship

for any real or imagined reason could certainly respond in a negative manner that could result in legal or reputational harm.

#### **Mitigation of Harms**

There are a number of ways for an organization to attempt to mitigate potential harms. It could, for example, devise a set of guidelines and policies and provide education proactively to residents, staff and families regarding sexuality needs of persons with dementia. Making the organization's own values and beliefs transparent is also essential. The organization should ensure all protective measures are put into place as required and that support is offered for emotional and moral distress whether on the part of the resident, staff or family member. It is also important that staff and family members be encouraged to not project their own values and beliefs onto the residents. Each resident should be provided with ample support to not only ensure they receive protection, but additionally to ensure their own values and beliefs regarding their sexual needs will be honoured whenever it is possible and appropriate to do so.

#### **Conclusion**

While there is no paucity of ethical issues concerning sexually active residents with dementia in long-term care, it is forging the appropriate relationship between autonomy and protection that is highly challenging. This article's intent has not been to provide an exhaustive identification and analyses of all complex issues, but rather to make transparent to the reader some of my own reflections of an ethicist working in this context. There is much more to say and learn about this topic, and the ageing boomer population will provide a somewhat different set of issues when nursing homes become populated by them. Additionally, we must ensure that we live up to the moral imperative of creating nursing home environments that are genuinely welcoming and prepared to meet the needs of the elderly who present with a range of gender and sexuality identities. To this end, we have much work to do.

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