

Intimacy and Dementia in the Long-Term Care Setting

By Joanne Kaldy

“Here come the baby boomers, so I think you expect a sexual revolution in nursing homes,” said Jim Wright, MD, PhD, CMD, medical director at Westminster Canterbury Richmond in Virginia, at the start of “Intimacy and Dementia in the Long-Term Care Setting,” a program at PALTC22 in Baltimore, MD, in March.

“Studies show that sexual intimacy is an important part of the lives of [older adults],” Dr. Wright said. He referred to one study from 2018 showing that 59% of partnered people with dementia of all ages are sexually active; of those between the ages of 80 and 91, the number is still fairly high at 40%. With more than half of all patients in nursing homes with dementia and concentrated in a congregate living situation, he suggested, it is important to address issues of intimacy. Yet, he said, “there are a lot of minefields, and a lot of eggshells to walk on.”

Not surprisingly, family, administration, and staff are all cautious about allowing sexual intimacy in the facility for several reasons, including various religious and cultural mores about sexual activity, privacy concerns, risk of harm to one or both partners, difficulty in determining consent, and risk of upsetting family members. Facilities are also concerned about the risk of citation by state surveyors and the potential for legal action against the facility.

The Empowerment of Impermanence

Dr. Wright talked about what he calls “the empowerment of impermanence,” a way to value the personhood of people living with dementia. He explained, “To identify the personhood of someone is to say, ‘I give you permission to change at every stage of life.’ Being a whole person means being allowed to express preferences today that are different from those in the past.” He stressed, “We are impermanent — and, of course, no one changes more or more quickly than someone with dementia.”

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While it is important to know who people were, “we empower them more by finding out who they are today,” Dr. Wright suggested. “Their past is important, but it’s more important to find out what their choices are now.” He further noted, “We empower our patients by allowing them to make changes to their previously expressed wishes.”

Specifically for people with dementia, Dr. Wright noted, “We can empower them by allowing their identity to continue to develop, letting them make choices inconsistent with their previous choices and values (or even their advance directives), and allowing their sexual preferences to change.” For instance, he shared the story of Justice Sandra Day O’Connor, whose husband had dementia, was in a facility, and had formed a romantic relationship with another woman. Justice O’Connor approved of the relationship because she wanted her husband to be happy, even as his dementia advanced.

Basic Rights, Wrongs

Ultimately, Peter Jaggard, MD, CMD, medical director at Presbyterian Homes in Evanston, IL, suggested, there are three basic rights of sexual behavior in dementia:

- The right to consensual sexual activity.
- The right to not have unconsented-to sexual aggression directed at oneself.
- The right to an authentic process of sexual consent capacity determination in dementia.

However, he also suggested that staff need to understand inappropriate sexual behavior (ISB) in dementia, which may stem from the normal desire for intimacy altered by behavioral and sexual disinhibition due to intracranial pathology. Specifically, he said that staff should be trained to recognize that ISB is usually due to disinhibition in dementia and that they should intervene before unwanted behaviors occur.

Nursing assessments should be conducted to assess for triggers, and strategies for redirection and maintaining the dignity of the resident should become part of the care plan. Dr. Jaggard stressed that the staff may often be targets of ISB by residents during daily care, so they need counsel and support.

It can be challenging to assess sexual consent in patients with dementia; these individuals often may become victims of sexual coercion due to fears of harm, abandonment, loss of emotional support, or loss of love by a partner. They also may have mistaken assumptions about the intent of a partner, or they may mistake someone for a spouse or significant other.

To assess sexual consent capacity, Dr. Jaggard said, it is important to determine the patient’s awareness of the relationship and the other person’s identity and evaluate the patient’s ability to avoid exploitation and awareness of potential risks.

Of course, there are legal aspects to consider as well. Elaine Healy, MD, explained, “Legal sexual activity requires consent, and consent requires capacity.” Many residents with dementia don’t have the capacity to consent by strict

legal criteria, she observed. However, she added, “requiring capacity/consent by conventional legal criteria will deprive some residents with dementia from the benefits of an intimate relationship at a time when there are few remaining potential sources of happiness and fulfillment.”

At the same time, the staff need to understand that people express love and intimacy in different ways. Dr. Jaggard

referred to the “five love languages,” expressions of how people feel love: acts of service, receiving gifts, quality time, words of affirmation, and physical touch (<https://www.5lovelanguages.com/>). ✎

Senior contributing writer Joanne Kaldy is a freelance writer in New Orleans, LA, and a communications consultant for the Society and other organizations.

AMDA White Paper on Sexual Consent

In 2016, AMDA – The Society for Post-Acute and Long-Term Care Medicine published a white paper, “Capacity for Sexual Consent in Dementia in Long-Term Care,” that addressed a number of relevant issues, including:

- Ethical rights regarding sexual activity, protection, and determination of capacity.
- Formal assessment of older adults with diminished capacity for consent.
- General considerations concerning evaluation of capacity to consent.
- Sexual consent capacity assessment.
- Perspectives of other disciplines working in long-term care.
- Perspectives from interdisciplinary team members.

Access the full white paper at <https://bit.ly/37EzyZx>.

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