

# Respect for Intimacy Among Persons Whose Privacy Is Compromised

Syeda Shanza Hashmi, BA, Jennifer Chandler, LLB, LLM, and J. Paul Fedoroff, MD

This invited commentary addresses an article by Joy and Weiss and their views on the potential use of sexual advanced directives “. . . as a theoretical mechanism to assert sexual desire past incapacity . . .” Their article focuses on the importance of the sexual rights of individuals with neurocognitive disorders, principally dementia, in which there is a progressive decrease in executive functioning leading to impaired communication, understanding, and judgment. Individuals with dementia may be increasingly challenged to maintain autonomy in life, such as in cases of financial decision-making, self-care, end-of-life care, and, as Joy and Weiss point out, decisions pertaining to sexual relations. They highlight a possible trend of placing increasing restrictions on the freedom of aging patients to have sexual intimacy, to ensure their safety, and to prevent the potential of sexual abuse or other forms of harm. They propose the development of a “hypothetical sexual advance directive” for those at risk for incapacity, in collaboration with forensic psychiatrists. Although we agree that sexual rights should be legally protected by the established principles of the right to govern one’s own body, rights of privacy, and autonomy, we are concerned that the requirement to have a signed and witnessed sexual advance directive may have unintended consequences that decrease, rather than enhance the sexual rights of people with dementia and other types of intellectual disabilities. We propose an alternative in which established and consensual sexual intimacy is treated as an aspect of the right to bodily self-determination that should not require an advance directive.

**J Am Acad Psychiatry Law 46:295–97, 2018. DOI:10.29158/JAAPL.003764-18**

Psychiatric advance directives are sometimes referred to as Ulysses contracts. In Homer’s epic poem *The Odyssey*,<sup>1</sup> Ulysses knew that if he and his crew succumbed to seduction by the female Sirens and sailed toward their island, they would be sailing to their deaths. To avoid falling prey to the Sirens, Ulysses directed that he be tied to the mast of his ship and told his crew to disobey any orders he might make while under the influence of the Sirens. This form of advance directive, in which Ulysses instructed his crew to obey his current wishes, even if he later changed his mind, has been the subject of considerable debate since it involves a decision that is irrevocable and therefore seems to defy one of the requirements of consent.<sup>2</sup>

In their thoughtful article, Joy and Weiss<sup>3</sup> reference the *Cruzan* case in the Supreme Court of the United States,<sup>4</sup> in which the Court ruled in support of the right to refuse life-sustaining treatment even after a patient becomes incompetent, because of the right to protection from “unwanted medical intervention” (Ref. 3, p 287). This ruling led to Congress’ implementing the Patient Self-Determination Act, in support of patients’ rights to assert their current wishes into the future through advanced directives or living wills. Health care providers are required to use these documents and also “to educate staff about them” (Ref. 3, p 287). The Canadian provinces also provide statutory mechanisms that allow patients to make advance directives that bind their substitute decision-makers in the context of personal care<sup>5</sup> and medical decision-making.<sup>6</sup>

Joy and Weiss<sup>1</sup> next discuss the “right to self-determination” for sexual activity (as opposed to end-of-life interventions), specifically for older patients with a diagnosis of dementia. They describe sexual activity as an individual right but argue, in a careful manner, that it needs to be asserted before incapacity (Ref. 3, p 287). They classify sexual activities as including “. . . kissing, touching, the erotic,

---

Ms. Hashmi is a Medical Student, Faculty of Medicine, University of Ottawa, and National Officer, Canadian Federation of Medical Students, Ottawa, Ontario, Canada. Ms. Chandler is Professor, Centre for Health Law, Policy and Ethics, Ottawa, Ontario, Canada. Dr. Fedoroff is Director of the Forensic Research Unit of the University of Ottawa Institute of Mental Health Research (UOIMHR), and Co-Director of the Sexual Behaviors Clinic, Royal Ottawa Mental Health Centre, Ottawa, Ontario, Canada. Address correspondence to: J. Paul Fedoroff, MD, Integrated Forensic Program, The Royal, 1145 Carling Avenue, Ottawa Ontario, K1Z 7K4. E-mail: Paul.Fedoroff@gmail.com.

Disclosures of financial or other potential conflicts of interest: None.

the romantic, and oral and penetrative sex itself in its many forms. . .” and also emphasize its importance “. . . across the life cycle” (Ref. 3, p 290). With a focus on people with dementia, they acknowledge that “. . .the simple act of conversation [is] difficult whereas touch and intimacy [are] more salient ways to relate” (Ref. 3, p 290) for such patients. Therefore, they contribute to positive health outcomes including “. . . improved self-esteem, cognitive functioning, relationships, mood, and independence” (Ref. 3, p 290).

Joy and Weiss<sup>3</sup> express concerns about the risk of abuse or violation of intimate physical contact with a cognitively impaired person, especially if the individual is incapable of consent during the act or in reporting after the act. They cite an article by Boni-Saenz<sup>7</sup> on sexuality and incapacity in a case involving a married couple. Mrs. Rayhons was diagnosed with Alzheimer’s disease and was moved to a residential care facility. Mr. Rayhons was found to be continuing to have sexual relations with her, despite her having a disease that staff believed prevented her from consenting. Mr. Rayhons was charged with sexual abuse, but after a trial that reviewed their relationship, including Mrs. Rayhons’ medical condition and their alleged sexual encounter, Mr. Rayhons was acquitted by the jury. In that case, there apparently was no way to assess whether Mrs. Rayhons, a cognitively impaired person, consented or withdrew consent during those private sexual encounters. Joy and Weiss<sup>3</sup> argue that this poses an ethics-related dilemma that may have been avoided by using proper assessment tools to examine Mrs. Rayhons’ perception of the sexual activities before and after visits. They also suggest that staff could have determined whether there were instances of abuse after intimate relations between a married couple. However, it is of interest that complaints about the alleged sexual activities of the couple arose only after Mrs. Rayhons was moved from a private room to a semiprivate one.

Joy and Weiss refer to comments by Dr. Robert Bender, who testified that in conditions such as Alzheimer’s, memory pathways, including those for sexual interactions “maintain functioning long after other areas decline” (Ref. 3, p 289). They argue that, in essence, in cases of neurocognitive disorders in which executive functions, such as communication and memory, are disabled, there can still be sexual expression and consent.

Citing Iowa’s Office of the State Long-Term Care Ombudsman (OSLTCO) they opine that it is important to implement a multidisciplinary approach in assessing these matters, especially when conclusions about a patient’s understanding of sexual interaction and consent are reached. The Ombudsman outlined such an approach, recognizing the highly individualized and variable nature of such cases (Ref. 3, p 290).

### Comment

In their article, Joy and Weiss have raised important concerns about the sexual rights of patients with dementia. The World Health Organization (WHO) has proposed that the term “sexual rights” refers to the application of well-established human rights such as privacy, equality, and self-determination of sexuality and sexual health.<sup>8</sup> Concerns similar to those considered by Joy and Weiss have been raised and discussed in the case of men and women with intellectual disabilities.<sup>9</sup> The cases reviewed by Joy and Weiss involved patients who had been institutionalized, thereby interfering with their right to privacy. The authors advocate for the development of a sexual advance directive instrument, together with associated formal capacity-assessment tools, to explore competency to consent to sexual activity.

Elderly people with and without dementia engage in consensual sexual activities every day with no complaints until one of them is admitted to an institution, such as a hospital or assisted-living facility. As discussed earlier, Henry and Donna Rayhons’ problems began only after Donna’s new roommate was disturbed when she thought she was overhearing their sexual activity. It was not the couple who had not consented, it was the roommate. Institutions have the responsibility to protect vulnerable people in their care. Because of this responsibility, as well as the stigma surrounding sexuality and the elderly, the default expectation is often that sexual activity has ceased or should cease upon institutionalization.

Accordingly, we endorse the spirit of the suggestions of Joy and Weiss, but are concerned by the potential unintended consequences of taking the formal legal approaches that they suggest. If these problems are approached through legal sexual advance directives and a consent-to-sex assessment tool, it would add to the perceived obligation of institutions to intrude on the private lives of the people whose rights they are expected to protect. Rather than

accepting and facilitating (through the provision of private spaces) continued sexual intimacy between elders who remain capable of consenting despite some diminishment of capacity, risk-averse institutions may insist on the completion of formal legal documents. If sexual advance directives are required, it is our prediction that many elderly couples would elect not to go through the process of disclosing their sexual interests and preferences to institutional staff, not because they do not have sexual desires but because of the necessary loss of privacy and autonomy inherent in the process. This feeling of loss of privacy would undoubtedly be even worse if it were advanced by “experts” whose field of expertise is forensic psychiatry.

We suggest that an approach inspired by WHO’s discussion of established human rights to privacy, equality, and self-determination in the context of sexual activity would be helpful. It would reorient the focus toward a presumption of continued interest in and entitlement to engage in sexual activity by elderly people who are institutionalized as a result of neurocognitive decline. In keeping with this approach, adults are assumed to be capable until the opposite is shown, and the level of capacity required varies by the particular decision to be made. The approach should be no different in relation to sexual activity. Greater clarity regarding the expectation that institutions respect and protect the sexual rights of patients to the extent possible, as part of the more general obligation to their patients, would counter the risk-averse position that all sexual activity should cease once a patient passes through institutional doors. The basic capacity to recognize one’s partner, to understand and appreciate the nature of the activity, and to communicate acceptance or dissatisfac-

tion with the activity, are probably necessary for valid consent. However, a person who has these basic capacities should not have to complete a formal legal instrument to be able to engage in sexual activity.

Of course, institutions involved in the care of people with dementia and other forms of cognitive impairment have an obligation to ensure the safety of the people in their care. Concerns that arise about abuse or exploitation should be addressed, including criminal prosecution if warranted. Forensic psychiatrists may play an important part in such investigations and subsequent treatment. However, we advocate that, like the government, forensic psychiatrists should stay out of the bedrooms of people who are suspect only because of impaired cognitive ability and a lack of privacy.

## References

1. Homer: *The Odyssey*. Translated by Robert Fagles. Introduction by Bernard Knox. New York: Penguin Books, 1996
2. Atkinson JM, Garner H, Patrick H *et al*: Issues in the development of advance directives in mental health care. *J Ment Health* 12: 463–74, 2003
3. Joy M, Weiss KJ: Consent for intimacy among persons with neurocognitive impairment. *J Am Acad Psychiatry Law* 46:286–94, 2018
4. *Cruzan v. Director*, 497 U.S. 261 (1990)
5. Substitute Decisions Act, 1992, S.O. 1992, c.30
6. Health Care Consent Act, 1992, S.O. 1992, c.2, Sched. A
7. Boni-Saenz A: Sexual advance directives. *Ala L Rev* 68:1–47, 2016
8. World Health Organization: *Sexual and Reproductive Health: Defining Sexual Health*. Geneva: WHO, Not dated. Available at: [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/). Accessed June 20, 2018
9. Fedoroff JP, Fedoroff B, Peever C: Consent to treatment issues in sex offenders with developmental delay, in *Ethical Dilemmas: Sexuality and Developmental Disability*. Edited by Griffiths D, Richards D, Fedoroff P, *et al*. Kingston, NY: NADD Press, 2002, pp. 356–86