

# Consent for Intimacy Among Persons With Neurocognitive Impairment

Michelle Joy, MD, and Kenneth J. Weiss, MD

The right to bodily self-determination has a firm foothold in American jurisprudence and legislation. Since the early 20th century, courts have consistently upheld individuals' rights to govern their bodies, citing the constitutional right to privacy and importance of individual autonomy. After these decisions, the advance directive has become an essential way to express personal preferences after incapacity for decision-making, especially in end-of-life scenarios. Can sexual preferences survive cognitive incapacity as well? When individuals lose the capacity to voice sexual needs and preferences, there is no mechanism to protect sexual expression. Dementia's ability to render individuals legally incapable of consenting to sexual activity was the focus of the case of Iowa legislator Henry Rayhons. The state charged Mr. Rayhons with assault for alleged sexual interactions with his wife, who had Alzheimer's disease. The prosecution failed to prove its case. We propose a hypothetical sexual advance directive as a theoretical mechanism to assert sexual desire past incapacity, grounded in claims regarding the possible importance of sex for individuals with neurocognitive disorders. Forensic psychiatrists can play a unique role in the creation and implementation of such a tool.

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In 1914, Chief Justice Benjamin Cardozo said of self-determination, "Every human being of adult years of sound mind has the right to determine what shall be done with his own body."<sup>1</sup> This decision in *Schloendorff v. Society of New York Hospital* required medical professionals to obtain consent for invasive medical procedures. Support for the right of self-determination regarding life-or-death medical decisions continued to gain momentum in the 1970s.<sup>2</sup> In the past, medical professionals had followed religious or philosophical reasoning that prioritized the preservation of life.<sup>2</sup> When capable of making and expressing them, patients' individual desires began to supplant medical authority in a series of decisions and statutes.

## Landmarks in Self-Determination Rights

In the 1976 case of *In re Quinlan*, the Supreme Court of New Jersey granted Karen Quinlan's father

the right to withdraw life-supporting treatments, given her persistent comatose condition.<sup>3</sup> The decision stated that an individual's constitutional right to privacy could not be disregarded because of a present inability to communicate choice. Karen Quinlan had previously stated that she was against extensive medical interventions in cases of terminal illness. Medical testimony discussing the then -informal practice of "do not resuscitate" orders was used to support Mr. Quinlan's effort to withdraw life-support, as was an *amicus* brief by a Roman Catholic bishop citing Pope Pius XII's 1957 defense of the withdrawal of treatment when directly or indirectly desired by a patient. The court construed the decision to remove life-sustaining treatment as a matter of protected privacy that could outweigh the state's own constitutional interest in the preservation of life: "We think that the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest," wrote Chief Justice Hughes in an opinion (Ref. 3, p 664) that rested on cases involving the protection of the use of birth control

Dr. Joy is Attending Psychiatrist, Corporal Michael J. Crescenz VA Medical Center, Philadelphia, PA. Dr. Weiss is Robert L. Sadoff Clinical Professor of Forensic Psychiatry, Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA. Address correspondence to: Michelle Joy, MD, Philadelphia VA Medical Center, 3900 Woodland Avenue, 7th Floor, Philadelphia, PA 19104. E-mail: michelle.t.joy@gmail.com.

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measures<sup>4</sup> and the decision to have an abortion<sup>5</sup> by the right to privacy.

Quickly following the *Quinlan* case, the 1976 California Natural Death Act statutorily allowed physicians to withhold or withdraw life support in terminal conditions, based on a patient's previously expressed and documented wishes.<sup>6</sup> This legislation supported the use of living wills: instruments permitting enactment of specific wishes about life support and other medical interventions when a person can no longer communicate these choices. Other states followed with living will statutes, citing arguments for the right to privacy as well as autonomy in medical decision-making.<sup>7</sup> In 1983, Pennsylvania created a new type of advance directive: the durable power of attorney for health care.<sup>2</sup> More flexible than the written living will, this advance directive allowed for the appointment of a substituted decision-maker regarding medical decisions and was not limited to terminal illness.<sup>8</sup> Many states subsequently enacted similar legislation.

The question about these directives and their use finally made its way to the Supreme Court of the United States. In 1983, a motor vehicle accident left 25-year-old Nancy Cruzan in a persistent comatose state.<sup>9</sup> Her parents sought to appeal the denial of a petition by the Supreme Court of Missouri to withdraw Ms. Cruzan's life-sustaining nutrition and hydration. The 1990 decision in *Cruzan v. Director, Missouri Department of Health* supported the right to refuse life-sustaining treatments after an individual becomes incompetent, given a Fourteenth Amendment interest in protection from unwanted medical intervention, but allowed states to set different standards and procedures for determining enactment of this right.<sup>10</sup> By this time, a substantial body of case law supported the right to refuse treatment, even in the presence of incompetence.<sup>11-14</sup> In some of these cases, substituted judgment was deemed appropriate for determining when treatment withdrawal was appropriate. However, in *Cruzan*, the Court held that Missouri could require clear and convincing evidence of a patient's wishes. The same year, Congress implemented the Patient Self-Determination Act to encourage communication regarding individual wishes toward removal of life-sustaining treatment.<sup>15</sup> The law required health care providers to document the existence of any advance directives, to educate staff about them, and not to discriminate based on their existence or absence.<sup>2,16</sup>

Throughout this timeline, the courts used language that emphasized a right to self-determination

that persists beyond incompetence. Another contemporary example of protected decision-making is the psychiatric advance directive. This tool provides an individual with the opportunity to document preferences regarding future psychiatric treatment if capacity to make such decisions is suspended or lost.<sup>17</sup> Such decisions may include accepting or refusing certain mental health treatments and voicing preferences regarding care location or type, including medications, specific physicians, seclusion, restraint, and electroconvulsive therapy.<sup>18</sup> The psychiatric advance directive may allow for the appointment of a substituted decision-maker in times of crisis, although revocation options may inhibit implementation.

### The Possibility of a Sexual Advance Directive

Is it possible that an individual could similarly assert a desire for sexual behavior that would survive incapacity? Might an instrument such as the advance directive be able to convey sexual preferences into the future? This sexual advance directive could be executed before the onset, or in the early stages, of dementia. The activation of this tool would presume a later loss of capacity, similar to medical and psychiatric advance directives.

Consensual sex is legally regarded as an intimate and private matter, not subject to oversight or regulation by the states. In *Griswold v. Connecticut*, the Supreme Court acknowledged a Constitutional right to privacy within marriage by the Fourteenth Amendment.<sup>4</sup> This fundamental right provided rationale for the Court's decision in *Lawrence v. Texas*, which held that sexual conduct of a consensual nature was a liberty protected by substantive due process under the Fourteenth Amendment.<sup>19</sup> The courts have also acknowledged a fundamental right to privacy regarding related concepts of marriage, family, reproduction, contraception, and overall freedom.<sup>20,21</sup> The same cases became legal precedent for decisions regarding medical advanced directives. Incompetent persons who have guardians appointed retain some rights, including marriage and voting, unless otherwise specified.<sup>21</sup> Sex is not customarily addressed. However, the 1987 Federal Nursing Home Reform Act ensured a right to privacy for residents of these facilities, and states often have bills of rights for nursing homes that encompass privacy.<sup>22</sup>

Consensual sexual activity is a constitutionally protected right that has precedent to proceed without intrusion of the government.<sup>21</sup> The hypothetical sexual advance directive would treat intimacy decisions as private matters highlighting the importance of self-determination according to the legacy of *Cruzan* and be a possible mechanism to prevent violation of an individual's rights. However, given that the right to private sex refers only to consensual sex, would implementation run afoul of criminal statutes? Because the law recognizes consent only at the time of intimate contact, would sexual interactions create negative legal consequences for partners? With regard to criminal liability for withdrawing life-sustaining treatment, the *Quinlan* court held that there could be no criminal homicide.<sup>3</sup> The court opined that even if the patient died, it was not unlawful killing, given that providers were third parties withdrawing treatment according to constitutionally protected rights. Nonetheless, it is difficult to answer these questions in regard to a potential sexual advance directive, and the state has an important interest in protecting vulnerable populations from harm, including that of a sexual nature.

Furthermore, although the courts have emphasized a right to self-determination regarding a person's right to refuse treatment, they have not similarly recognized a right to medical assistance in dying. Landmark cases *Glucksburg v. Washington*<sup>23</sup> and *Vacco v. Quill*<sup>24</sup> established that there is no equal protection or due process right to assisted suicide under the Fourteenth Amendment. The decisions allowed states to develop their own policies on medical aid in dying, and Oregon, Washington, Vermont, California, and Colorado have followed with laws allowing individuals to request medication to end life in certain terminal situations.<sup>25</sup> However, the overarching legal principle has remained that states have a valid interest in outlawing assisted suicide and that a person does not have a right to obtain assistance in committing suicide. This case legacy is important because it demonstrates legal boundaries that remain with respect to self-determination and one's health.

### Controversies Surrounding Sex, Dementia, and Consent

Aging individuals who develop neurocognitive disorders may lose the capacity to consent to sex. For the United States population in general, this ability

has typically been equated with cognitive performance, which may be narrowly defined statutorily (in conditions such as frank unconsciousness) or more broadly described as related to overall mental soundness.<sup>26</sup> Evaluation of the ability to consent to sex tends to occur in legal settings in cases of sexual assault. Courts may consider a range of factors, such as understanding and communicating the decision to engage in sexual behavior; broad evidence of the ability to reason; one's capability to understand the nature of sex, its consequences, and physical mechanics; or even the ability to acknowledge its meaningfulness and moral dimensions.<sup>21,26</sup> Although an individual's competency is presumed intact unless adjudicated otherwise, perpetrators may be prosecuted for engaging in a sex act with a victim who does not or is not able to consent. In medical settings, there is no agreement as to how to assess capacity for sexuality.<sup>27</sup> In general, approaches to assessing competence tend to focus on cognitive capacities about sexual behavior, which takes place in the often-indescribable realms of bodily pleasure.

Although conservative approaches to sexual competency may protect vulnerable individuals, they could permanently eliminate the possibility of intimate interactions for populations such as those with dementia or other forms of persistent cognitive impairment. Even if individuals manifest apparent desire for sexual interaction, those with dementia are often legally incompetent to consent to such activity. A person having intimate physical contact with such a cognitively impaired individual may be subject to criminal prosecution for sexual assault if there are allegations that the victim had not consented or was unable to consent.<sup>28</sup>

The literature contains relevant discussions on sexual consent among persons with intellectual disability or serious mental illness. Disability rights scholar Michael Perlin has written extensively on the important nature of recognizing sexual rights for these populations.<sup>20,29,30</sup> He argues that the topic is not sufficiently addressed at the institutional level but that individuals with mental disabilities may have sexual desires and rights worthy of protection.

There is also a small related body of literature regarding consent for fringe sexual practices. These papers point to the legal handling of instances as important in marking the contours of sexual autonomy apart from state intervention.<sup>31,32</sup> The question of whether a person can consent to continued sexual

interaction once incapacitated from previously desired and negotiated erotic asphyxiation bears weight on whether anyone can consent to intimacy in advance of incapacity as well as whether partners can and should be prosecuted.

### **Marital Intimacy or Sexual Assault?**

The case of Henry Rayhons highlights the conflict regarding individuals with dementia as a population that may have coexisting needs for protection from harm and rights for sexual expression. In April 2015, a jury acquitted 78-year-old former Iowa state representative Henry Rayhons of sexually abusing his wife.<sup>33</sup> Their story did not start there, however. Henry and Donna Rayhons, both widowed, met at church in 2007 and married shortly thereafter. Mrs. Rayhons started to show signs of Alzheimer's disease in 2010. In March of 2014, she was admitted to a nursing home while her husband, a farmer and Iowa legislator, continued living in the community. Reports indicated that they had a loving relationship and that he visited her often.

Mrs. Rayhons' daughter from a previous marriage was her health care proxy, and later, her appointed guardian, and she requested a medical examination of her mother's mental capacity. In April 2014, Mrs. Rayhons scored a 2 of 15 on a general cognitive test included in the Minimum Data Set for nursing facility residents (the Brief Interview for Mental Status [BIMS])<sup>34</sup>; the following month she scored 0 of a possible 15 in response to questions about orientation and short-term memory registration. Without a specific capacity assessment, in May of 2014, Mrs. Rayhons' attending physician determined that she did not have the capacity to consent to sex and conveyed his opinion to her husband. She was then moved to a semiprivate room. Approximately eight days after the examination, Mrs. Rayhons' roommate reported hearing noises in the adjacent bed while Mr. Rayhons was visiting. With further progression of her dementia, Mrs. Rayhons died on August 8, 2014. Days later, Mr. Rayhons was arrested on felony charges of third-degree sexual abuse. He elected to stand trial.

### **Trial Testimony**

Mr. Rayhons denied breaking the law. The *Washington Post* reported: "Rayhons pleaded not guilty to the charges, testifying that all he had done on the night in question was pray, hold hands and kiss."<sup>35</sup>

He confessed to detectives, he said, because their questions confused him. Mrs. Rayhons' roommate was not sure if what she had heard was sexual. DNA evidence was negative.<sup>36</sup> The physician from Concord Care Center, Dr. John Brady, concurred with other prosecution witnesses that Mrs. Rayhons had severe dementia.<sup>36</sup> Calling the patient's positive response to her husband's affection "primitive," like that of a baby, the doctor added, "I don't believe an infant makes an informed decision." It was Dr. Brady who had previously declared Mrs. Rayhons incapable of consenting to sex. A neurological expert for the prosecution, Dr. Alireza Yarahmadi, also distinguished capacities of persons with Alzheimer's: "They do have feelings, but they don't have good judgment."<sup>37</sup>

Defense attorney Joel Yunek presented expert testimony by a family practitioner specializing in geriatrics and memory.<sup>38</sup> Dr. Robert Bender told the jury that there are memory pathways deep inside the brain that are less affected by Alzheimer's disease than executive functioning is, including those for social interactions. Social contact, he said, is the most important part of healthy aging and includes sexual contact. These modes of interacting, and the pleasure derived therefrom, are mediated by deep centers of the brain, such as the hypothalamus. Dr. Bender described that these regions maintain functioning long after other areas decline:

[F]rom a basic science perspective, one of the reasons that doctors like me are admonished to remember that human beings are sexual their whole lives and that these centers are active and that we should acknowledge this and it is a part of being human, a very, very basic part of being human [Ref. 38, p 17].

The capacities cited, Dr. Bender added, would not be manifest on the BIMS test that Donna Rayhons had been given: "To rely on a BIMS score to assess whether a person is capable of or should be allowed to have sexual contact would be a medical mistake" (Ref. 38, p 19). Even a person with a zero on the BIMS could still be capable of enjoying emotions and sexual arousal. Though he did not examine Mrs. Rayhons, Dr. Bender testified that, based on the records, she would have been capable of consenting to sex with her husband and of refusing.

### **Policy in Iowa**

In October 2015, Iowa's Office of the State Long-Term Care Ombudsman (OSLTCO) issued a

memorandum to nursing facility administrators.<sup>39</sup> It stated, in part:

Though outcomes to sexually-related situations vary innumerable, as each is different and must be considered independently, the OSLTCO believes a multidisciplinary effort is necessary to develop a thoughtful process from which to draw and support conclusions. It is not the responsibility of the long-term care facility or assisted living program (or a single staff member) to solely determine whether a resident/tenant should or should not be sexually expressive. If a resident's/tenant's safety or capacity to consent is in question, the interdisciplinary care team must collectively assess the individual's level of capacity to determine benefits or potential risks associated with the act. Residents/tenants who maintain cognitive capacity to consent should be afforded the same rights to privacy, respect, and freedom to sexual expression as they would if they were living in the community [Ref. 39, p 2].

It is apparent that Iowa's ombudsman structured the guidance such that capacity determinations were a threshold for permitting sexual expression and that the manner of assessment would be locally driven. In the sample guidelines that followed,<sup>40</sup> individuals with reduced capacity could be competent: "Consent may be evidenced through the language, gestures, conduct, activities or other affirmative actions of a resident/tenant who: 1. exhibits cognitive decision-making capacity; or 2. exhibits diminished cognitive decision-making capacity (e.g., neurocognitive disorders such as Dementia/Alzheimer's Disease)" (Ref. 40, p 1). The document explicitly states that acting upon an incapacitated person or one incapable of providing consent is a criminal offense, per Iowa Code § 709.1 (2016). All persons with known neurocognitive impairment must be assessed for competency, and some individuals with intact cognitive capacity may be assessed for ongoing capacity. Thus, under Iowa's post-*Rayhons* guidance, there would be no room for sexual expression based on an advance directive without present capacity.

### Sexuality in the Elderly: The Evidence

A sexual advance directive is only a worthwhile consideration if sex is important in the lives of elderly individuals. Sexual expression can include a range of activities, including kissing, touching, the erotic, the romantic, and oral and penetrative sex itself in its many forms, all of which can be important for an individual's quality of life across the life cycle.<sup>41</sup> Posited mechanisms include sexuality as a form of communication, a way to relieve stress, a mode of feeling alive, and a method of sharing caring feelings.<sup>42,43</sup> In

aging populations, sexual activity may remain an important source of pleasure when other avenues of gratification are less accessible as the body and mind decline. In fact, avenues of experiencing pleasure have been described as diminishing after most other biological processes.<sup>44</sup>

Nursing home residents are often coping with losses of their homes and relationships with dying family and friends. In dementia, even the simple act of conversation may become difficult, whereas touch and intimacy become more salient ways to relate. Intimate physical contact can be a way to show love and caring between two people when loneliness and isolation threaten, and blanket bans on sexuality have been said to cause "iatrogenic loneliness."<sup>45</sup>

Touted positive health outcomes correlated with sexual interactions include improved self-esteem, cognitive functioning, relationships, mood, and independence.<sup>43,46</sup> Sexuality has been portrayed as "central to an individual's health and well-being."<sup>42</sup> In populations with intellectual disabilities, general self-determination has also been correlated with having higher quality of life.<sup>47</sup>

Sexuality among older adults often faces stigma. Many perceive it to be nonexistent, humorous, or disgusting.<sup>48</sup> Elderly citizens, nevertheless, including those in care facilities, appear to be more interested and engaged in sexuality than imagined. The frequency of sex tends to decrease over time, but sexual interest persists among elderly individuals. In studies, frequency of sex among senior individuals is variously estimated as more than 25 percent of people 75 years of age having sex at least once a month (with an average of three times a month),<sup>49</sup> 46% 70- to 80-year-olds having at least one orgasm a month,<sup>50</sup> and many over 70 characterizing sex as moderately to extremely important.<sup>51</sup> Sex is sometimes framed as important, even in relationships where one partner has dementia.<sup>52</sup> In addition, individuals who are not sexually active may still want to be.<sup>53</sup> Given the large and expanding population of elderly individuals in the United States, including those in nursing homes and those with dementia, there is a significant number of individuals who remain sexually active and interested, but may be barred from participating.

Sex among elderly residents in care facilities has typically been dismissed as a possibility and framed with expectations of abstinence. In a small observational study of elderly individuals with dementia in structured care settings, investigators noted sexual

interactions between residents.<sup>54</sup> The residents' family members were often angry about such interactions, especially with female residents. In a survey of over 350 nursing home directors, approximately 71 percent identified sexual concerns in their care settings, 58 percent noted resident-with-resident sexual activity, 60 percent stated there was masturbation, 12 percent required family consent, and 63 percent had no policies regarding sexual interactions.<sup>55</sup>

### Newer Approaches

Alternate models of addressing sexual consent capacity in the elderly have been proposed. A hypothetical "cognition-plus" test would include one's personal volition and decision-making network of support for consideration of sexual activity.<sup>26</sup> Committee approaches to balancing potential harm, autonomy, dignity, and sexual expression have also been proposed,<sup>27</sup> as have various formal medical assessment models; factors include safety, social appropriateness, the ability to express unwillingness to engage, and legal standards such as the meaningfulness of sex.<sup>21</sup>

The Hebrew Home at Riverdale care facility has developed a policy that acknowledges the importance of emotional and physical intimacy, upholds sexual choices, and espouses a right to engage in sexual activity.<sup>56</sup> It allows those with dementia to consent through words and affirmative actions indicating desire. The Hebrew Home's guidelines for assessing consent consider one's ability to express choices, including indications of pleasure, verbal and nonverbal communication, and mood before and after sexual contact; appreciation of sexual activity, including its meaning; personal quality-of-life considerations, including privacy rights, relationship history, the impact of permanent cognitive impairment, and responsibility to uphold individual choices.<sup>57</sup> It also describes decision-making procedures for crimes, sexual abuse, and inappropriate sexual activity. Both the policy and the guidelines are directly highlighted from the front page of the institution's website under a heading that reads "sexual expression policy."<sup>56</sup> Both best interest and substituted judgment standards have been proposed for considering sexual activity in someone deemed incapable of providing express consent.<sup>27</sup>

In recent years, sexual advance directives have been proposed and even strongly supported. In a 2016 article,<sup>58</sup> Boni-Saenz, stated: "The central

claim of this Article is that the law should recognize *sexual advance directives* for people with persistent acquired incapacity living in long-term care institutions" (Ref. 58, p 4, emphasis in original). This work can be referenced for further discussion of sexual advance directives regarding theories of sexual consent and a more thorough exploration of parallels in criminal law, fiduciary law, and the law of wills.

End of Life Washington has proposed a dementia/mental health directive that addresses "preferences for future intimate relationships for yourself."<sup>59</sup> The approach documents preferences for continuing and starting intimate relationships. A thorough and considerate approach, the document touches upon complicated topics such as sexual functioning, decline of memory, and wishes of partners, as well as moral, religious, and ethics values (alongside other nonintimate preferences regarding treatment, finances, and pets, among others). Although the document's preface states that it has "been reviewed by elder law attorneys, geriatric care managers, psychologists, and other experts," jurisprudence remains unsettled. Furthermore, the document is specific to Washington state. We support the spirit of End of Life Washington's approach from the perspective of forensic psychiatry, but we recommend continued conversation about potential abuses and negative legal outcomes.

### Potential Concerns

This discussion must include thoughtful consideration of potential abuse and vulnerability of the elderly and the *parens patriae* obligation of the state to protect this population. Abuse of the elderly, including sexual abuse, is a significant public health concern.<sup>60</sup> Persons can be charged with battery or rape or both for forcible sexual interactions, or for statutory rape, if the victim is unable to consent. One may argue, however, that actions permitted by other advance directives would constitute criminal or civil transgressions if not articulated in advance, such as withholding life support (murder, manslaughter) or performing invasive medical procedures (assault and battery).

In addition, it is important to remain vigilant for the potential of using a sexual advance directive to support sexual abuse of the elderly. One could imagine repeat encounters of a sexual nature that are distressing to a person with dementia, sexual acts or couplings a person may never have envisioned or wanted, utilization of intimacy for financial exploi-

tation, and a host of other detrimental outcomes perceived to be supported by an advanced directive. Checks against abuse could include the possibility for judicial discharge, not enforcing violations of public policy, and protected enactment only when the individual appears volitional and comfortable without signs of physical or emotional distress. With no sexual advance directive in place, the usual methods for determining capacity and protecting vulnerable individuals would take place.

A separate concern regards hypersexual behavior in individuals with frontotemporal dementia, behavioral variant (bvFTD).<sup>61</sup> This condition may be associated with increased libido and inappropriate behavior, not limited to sex. In a residential care setting, there is a risk that patients with bvFTD could take advantage of others with cognitive impairment or that they could exploit the authority of an advance directive to accommodate their enhanced impulses. Such an event could lead to serious consequences for patients and facilities.

## Discussion

Sexual interactions among older adults, including those with neurocognitive disorders, may improve quality of life and confer unique health and other benefits. Continued desire may survive cognitive impairment and the ability to consent. A sexual advance directive is proposed as a hypothetical method to enhance the quality of life and protect rights of privacy self-determination for individuals with dementia with a focus on drawing attention to the needs of this population. Although legal reviews have sketched out alternative judicial and legislative approaches to consent in cognitively incapacitated populations and medical literature has demonstrated a need for attention to sexuality in the elderly, this article considers both, highlighting the role of forensic psychiatrists in fostering discussion of policy and practice.

There is likely to be a range of reactions to this idea, given the nature of the topic at hand, including plenty of negative responses: sex is taboo, elderly individuals having sex is thought to be distasteful, and sexual assault is a crime. Cases like Henry Rayhons' nonetheless ask us to think deeply about potential ways in which individuals can remain intimate into old age, perhaps even with dementia. Case law and statutory precedent exist for the interrelated concepts of advance directives, informed consent, and a right

to bodily self-determination. However, most legal thought in these arenas involves health care generally and end-of-life treatment specifically. Positing that a sexual advance directive would be helpful for one's psychological and physical health, but hedonic pleasure also looms large in this equation (but not in other types of advance directives). Are we willing to allow individuals to assert their preferences regarding sensuality into the future? And if not, is there a logical and articulable reason for partitioning this domain of life experience? Although the proposal is hypothetical in nature, the questions and concerns that it raises are relevant to the lives of many elderly individuals.

Further collaboration with legal scholars and policy makers could determine the feasibility and logistics of this approach. Forensic psychiatrists can explore the possibility of such an instrument and, once field tested, advocate for a national conversation about its applicability. In the early phases of creating an advanced directive tool, forensic psychiatrists could work with legal scholars to explore the framework for the instrument itself. Whereas attorneys can make suitable contributions to the language of the instrument, forensic psychiatrists can operationalize the specific capacity and the particular nuances surrounding intimacy as a complex behavior and set of decisions. There would be a need for developing a formal capacity assessment of sexual behaviors among the elderly and for associated instruments, including scales, questionnaires, or advance directive prototypes. Then forensic psychiatrists could play a role in educating clinical professionals, including other psychiatrists, geriatricians, neurologists, and internists, about how and why the tool might be useful for their patients. Because of the tendency to ignore or even degrade the idea of sexuality in the elderly, implementation would require strong advocates who are knowledgeable about advance directives, capacity, and mental diseases to answer questions and anticipate resistance. Forensic psychiatrists should be knowledgeable about the intersection of these various topics as the potential for expert opinions is likely to grow. Cases may include criminal charges for sexual assault, civil liability of nursing homes for sexual interactions among residents, or physicians' standard of care for assessing sexual capacity in patients. As forensic psychiatrists who speak the languages of both law and medicine, we can act as translators between practitioners of both fields.

## References

1. Schloendorff v. Society of New York Hospital, 105 N.E. 92 (N.Y. 1914)
2. Brown BA: The history of advance directives: a literature review. *J Gerontol Nurs* 29:4–9, 2003
3. *In re Quinlan*, 355 A.2d 647 (N.J. 1976)
4. *Griswold v. Connecticut*, 381 U.S. 479 (1965)
5. *Roe v. Wade*, 410 U.S. 113 (1973)
6. Redleaf DL, Schmitt SB, Thompson WC: The California Natural Death Act: an empirical study of physicians' practices. *Stan L Rev* 31:913–45, 1979
7. Gelfand G: Living will statutes: the first decade. *Wis L Rev* 5:737–822, 1987
8. Lee MA, Berry K: Abuse of durable power of attorney for health care: case report. *J Am Geriatr Soc* 39:806–9, 1991
9. *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261 (1990)
10. Beauchamp TL: The right to die as the triumph of autonomy. *J Med Philos* 31:643–54, 2006
11. Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977)
12. *Matter of Storar*, 420 N.E.2d 64 (N.Y. 1981)
13. *Matter of Conroy*, 486 A.2d 1209 (N.J. 1985)
14. *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989)
15. Hoge SK: The patient self-determination act and psychiatric care. *J Am Acad Psychiatry Law* 22:577–86, 1994
16. Greco PJ, Schulman KA, Lavizzo-Mourey R, *et al*: The Patient Self-Determination Act and the future of advance directives. *Ann Intern Med* 115:639–43, 1991
17. Swanson J, Swartz M, Ferron J, *et al*: Psychiatric advance directives among public mental health consumers in five US cities: prevalence, demand, and correlates. *J Am Acad Psychiatry Law* 34:43–57, 2006
18. *Hargrave v. Vermont*, 340 F.3d 27 (2d Cir. 2003)
19. *Lawrence v. Texas*, 539 U.S. 558 (2003)
20. Perlin ML, Lynch AJ: "All his sexless patients": persons with mental disabilities and the competence to have sex. *Wash L Rev* 89: 257–300, 2014
21. Graves S: Let's talk about sex: a call for guardianship reform in Washington State. *Seattle J Soc Just* 14:477–520, 2015
22. Knaplund KS: The right of privacy and America's aging population. *Denv U L Rev* 86:439–56, 2009
23. *Washington v. Glucksburg*, 521 U.S. 702 (1997)
24. *Vacco v. Quill*, 521 U.S. 793 (1997)
25. Patients Rights Council: Assisted Suicide Laws in the United States. Steubenville, OH: Patients Rights Council. Last updated January 6, 2017. Available at: <http://www.patientsrightscouncil.org/site/assisted-suicide-state-laws/>. Accessed September 12, 2017
26. Boni-Saenz AA: Sexuality and incapacity. *Ohio St L J* 76:1201–53, 2015
27. Wilkins JM: More than capacity: alternatives for sexual decision making for individuals with dementia. *Gerontologist* 55:716–23, 2015
28. Pineau L: Date rape: a feminist analysis. *Law & Phil* 8:217–43, 1989
29. Perlin M, Lynch AJ: Sexuality, Disability, and the Law: Beyond the Last Frontier? New York, Palgrave Macmillan, 2016
30. Perlin ML: Hospitalized patients and the right to sexual interaction: beyond the last frontier. *NYU Rev L & Soc Change* 20:517–47, 1992
31. Busby K: Every breath you take: erotic asphyxiation, vengeful wives, and other enduring myths in spousal sexual assault prosecutions. *Can J Women Law* 24:328–58, 2012
32. Olson I: Asking for it: erotic asphyxiation and the limitations of sexual consent. *Jindal Global L Rev* 4:171–200, 2012
33. Belluck P: Iowa man found not guilty of sexually abusing wife with Alzheimer's. *Health*. New York Times. April 23, 2015, A18
34. Centers for Medicare and Medicaid Services: Long-Term Care Facility Resident Assessment Instrument 3.0 User's Manual, Version 1.14. Chapter 3: MDS Items, Section C: Cognitive Patterns. Atlanta, GA: CMS October 2016, pp C-1–C-16. Available at <https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/nursinghomequalityinits/mds30raimanual.html>. Accessed May 4, 2017
35. Kaplan S: Former Iowa legislator Henry Rayhons, 78, found not guilty of sexually abusing wife with Alzheimer's. *Washington Post*, April 23, 2015. Available at <http://www.washingtonpost.com/news/morning-mix/wp/2015/04/23/former-iowa-legislator-henry-rayhons-78-found-not-guilty-of-sexually-abusing-wife-with-alzheimers/>. Accessed October 18, 2015
36. Leys T: Doctor testifies to Donna Rayhons' mental state. *Des Moines Register*, April 13, 2015. Available at <http://www.desmoinesregister.com/story/news/2015/04/13/henry-rayhons-trial-mental-health-sex-abuse/25726131/>. Accessed October 18, 2015
37. Belluck P: Sex, dementia and a husband on trial at age 78. *New York Times*, April 13, 2015. Available at <https://www.nytimes.com/2015/04/14/health/sex-dementia-and-a-husband-henry-rayhons-on-trial-at-age-78.html>. Accessed July 17, 2015
38. *State of Iowa v. Henry Rayhons*. Trial transcript of the testimony of Robert Bender. Hancock County Courthouse, Garner, IA, April 17, 2015
39. Clingan-Fischer D: Memorandum re resident and tenant sexual expression, October 23, 2015. Office of the State Long-Term Care Ombudsman, Des Moines, IA, October 23, 2015. Obtained as part of the court proceedings in *Iowa v. Rayhons*, Defendant's Exhibit L from attorney Joel Yunek, November 12, 2015
40. Iowa Department on Aging: Resident/tenant sexual expression policy. Des Moines, IA: Iowa Department on Aging; undated; posted online January 26, 2017. Available at [https://www.iowaaging.gov/sites/default/files/library-documents/Sample%20Resident\\_Tenant%20Sexual%20Expression%20Policy.pdf](https://www.iowaaging.gov/sites/default/files/library-documents/Sample%20Resident_Tenant%20Sexual%20Expression%20Policy.pdf). Accessed May 4, 2017
41. McAuliffe L, Bauer M, Nay R: Barriers to the expression of sexuality in the older person: the role of the health professional. *Int J Older People Nurs* 2:69–75, 2007
42. Tarzia L, Fetherstonhaugh D, Bauer M: Dementia, sexuality and consent in residential aged care facilities. *J Med Ethics* 38:609–13, 2012
43. Tenenbaum EM: To be or to exist: standards for deciding whether dementia patients in nursing homes should engage in intimacy, sex, and adultery. *Ind L Rev* 42:675–720, 2009
44. Roach SM: Sexual behaviour of nursing home residents: staff perceptions and responses. *J Adv Nurs* 48:371–9, 2004
45. Miles SH, Parker K: Sexuality in the nursing home: iatrogenic loneliness. *Generations* 23:36–43, 1999
46. Hajjar RR, Kamel HK: Sexuality in the nursing home, part 1: attitudes and barriers to sexual expression. *J Am Med Dir Assoc* 5:S43–7, 2004
47. Lachapelle Y, Wehmeyer ML, Haelewyck MC, *et al*: The relationship between quality of life and self-determination: an international study. *J Intellect Disabil Res* 49:740–4, 2005
48. Kessel B: Sexuality in the older person. *Age Ageing* 30:121–4, 2001
49. DeLamater J, Moorman SM: Sexual behavior in later life. *J Aging Health* 19:921–45, 2007
50. Helgason AR, Adolfsson J, Dickman P, *et al*: Sexual desire, erection, orgasm and ejaculatory functions and their importance to

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- elderly Swedish men: a population-based study. *Age Ageing* 25: 285–91, 1996
51. Gott M, Hinchliff S: How important is sex in later life? The views of older people. *Soc Sci Med* 56:1617–28, 2003
  52. Derouesné C, Guigot J, Chermat V, *et al*: Sexual behavioral changes in Alzheimer's Disease. *Alzheimer Dis Assoc Disord* 10: 86–92, 1996
  53. White CB: Sexual interest, attitudes, knowledge, and sexual history in relation to sexual behavior in the institutionalized aged. *Arch Sex Behav* 11:11–21, 1982
  54. Ehrenfeld M, Bronner G, Tabak N, *et al*: Sexuality among institutionalized elderly patients with dementia. *Nurs Ethics* 6:144–9, 1999
  55. Lester PE, Kohen I, Stefanacci RG, *et al*: Sex in nursing homes: a survey of nursing home policies governing resident sexual activity. *J Am Med Dir Assoc* 17:71–4, 2016
  56. Dessel R, Ramirez M: Policies and procedures concerning sexual expression at the Hebrew Home at Riverdale. Riverdale, NY: The Hebrew Home at Riverdale. Revised April 2013. Available at <https://webcache.googleusercontent.com/search?q=cache:qE4XogYZ1B4J:https://static1.squarespace.com/static/5520af09e4b0c878b5733095/t/56328f20e4b04afbbe92827d/1446154016232/sexualexpressionpolicy.pdf+%&cd=1&chl=en&ct=clnk&gl=us>. Accessed May 5, 2017
  57. Abuse or Intimacy: Older Adult Sexuality. Riverdale, NY: Harry and Jeanette Weinberg Center for Elder Abuse Prevention (now the Center for Elder Justice) and The Hebrew Home at Riverdale, 2011. Available at <http://static1.squarespace.com/static/5520af09e4b0c878b5733095/t/56329028e4b0eaf99e2c2b71/1446154280079/sexualconsentguidelines.pdf>. Accessed August 14, 2016
  58. Boni-Saenz A: Sexual advance directives. *Ala L Rev* 68:1–47, 2016
  59. End of Life Washington: Alzheimer's Disease and Dementia Mental Health Advance Directive. Seattle, WA: End of Life Washington, undated. Available at: <https://endoflifewa.org/alzheimers-diseasedementia-advance-directive/>. Accessed September 11, 2017
  60. Acierno R, Hernandez MA, Amstadter AB, *et al*: Prevalence and correlates of emotional, physical, sexual, and financial abuse and potential neglect in the United States: The National Elder Mistreatment Study. *Am J Public Health* 100:292–7, 2010
  61. Torrisi M, Cacciola A, Marra A, *et al*: Inappropriate behaviors and hypersexuality in individuals with dementia: an overview of a neglected issue. *Geriatr Gerontol Int* 17:865–74, 2017