

Review Article

Sex in Geriatric Care Facilities: Sexual Violence or Self-Determination?

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Abstract

Maintaining intimacy is recognized as an integral aspect of aging. Benefits of intimate touch can be appreciated after cognitive decline in other areas, which can be a significant quality of life issue for couples. While interest in sexual activity varies among older adults, whether the capacity to consent to intimacy is preserved in individuals with neurocognitive impairment is a salient issue. While consent may not be problematic among couples living in their own homes, care facilities must be more protective. As a rule, sexual assault exists where there is no consent, placing the nonimpaired participant at risk for receiving criminal charges. In this article, we examine the tension between concepts of privacy and self-determination on one hand and legal constraints on the other. Long-term care facilities have begun to confront the delicate balance between compassionate permission to allow sexual behavior and legalistic proscriptions. We endorse that care facilities have policies about residents being intimate within their walls. We also suggest that individuals who are cognitively intact consider drafting advance directives to make their wishes for intimacy known for future instances where capacity to consent may be questioned. The concept of the sexual advance directive is an extension of law and policy that have been in place for decades. There remains a question of whether consent to sex can be given via substituted judgment, since there would have to be an exception in the criminal law.

Keywords

- Self-determination
- Advance directive
- Consent to sex
- Late-life sex

ABBREVIATIONS

NCD: Neurocognitive Disorder; AD: Advance Directive; PAD: Psychiatric Advance Directive; SAD: Sexual Advance Directive; IC: Informed Consent

INTRODUCTION

The concept of self-determination in medical care has been a cornerstone of patients' rights since the early twentieth century [1]. The idea formally took root in America with litigation about health professionals' duty to inform patients about the risks, benefits, and alternatives to the treatment under consideration; that is, what is now known as the doctrine of informed consent (IC). Over the years, IC has become standard, and in fact compulsory, in clinical care and in research [2]. Alongside the evolution of IC has been case law and legislation concerning matters such as the removal of life-sustaining interventions [3], physician-assisted suicide [4], and the right of citizens to govern their bodies and reproductive systems [5]. Following landmark cases such as Quinlan [3] and Cruzan [6], self-determination by way of the advance directive (AD) and substituted judgment became embedded in practice [7]. The United States Congress passed the Patient Self-Determination Act of 1990, which required that patients under federally-sponsored programs participate in healthcare decisions [8]. Issues concerning how patients would direct treatment or end-of-life decisions have been handled routinely through ADs. For example,

most hospitals request or require that competent patients complete an AD (living will or durable power of attorney), which becomes activated in the event that the patient becomes cognitively incapacitated. Even so, the benefits of this legislation have been underutilized, possibly due to misunderstandings and lack of education of patients and their families, with estimates of use among American adults at 10–25% as of 1995 [9]. Lack of attention to the AD is associated with problems such as litigation when family members are not in accord, obstacles providers face in making the best choices, and excessive cost during end-of-life decisions deliberations. For example, in the case of Nancy Cruzan [6], it was estimated that the cost of care in 1990 was \$112,000 per year [9], during which she had essentially no discernible quality of life.

Alongside the general AD for hospital, care facility, and end-of-life matters, there was awareness that later mental health care could also be directed by the patient [10,11]. This would involve a competent patient directing how to proceed when a later episode of serious mental illness affects capacity to make rational decisions consistent with their values. Such documents, often called psychiatric advance directives (PAD), can be instructional (living will) or proxy types. In the instructional PAD, the patient states how caregivers should respond. In the proxy type, the patient appoints a person to make decisions in a manner consistent with the patient's wishes [12,13]. As of 2019, 25 American states have specific PAD procedures; in others, individuals can adapt ordinary

AD formats for mental health purposes [12]. It is fair to conclude that these instruments, intended to promote autonomy and self-determination among persons with mental illness, are rarely used. With this history and these considerations in mind, we turn to a related question: whether individuals can exercise self-determination in the sexual domain. As we will discuss, sexual and nonsexual touch, as well as general physical intimacy, are features of human life that may outlast cognitive functioning despite their importance. Practical, esthetic, moral, and legal factors, however, may militate against the implementation of sexual practices in couples where one is impaired by neurocognitive disorder (NCD, formerly dementia). The salient issue, from a legal standpoint, is the operational definition of sexual assault (rape): sexual contact with a nonconsenting individual, including those incapacitated by illness; or persons who are asleep, intoxicated, intellectually disabled, or lacking mental capacity to appreciate the right to bodily integrity). In this article, we will suggest that competent individuals drafting ADs can incorporate sexual needs. How this can be accomplished without triggering a criminal investigation is at the medico-legal frontier.

Sexuality, Privacy, and Quality of Life

In medical/nursing settings, unauthorized touching can constitute battery (for example, elder abuse). It is obvious that such acts, done for the gratification of the abuser, are a form of unlawful contact. Significant criminal penalties attach to abuse of patients by medical personnel, incapacitated persons, and older adults. While nonconsensual sexual touch is against the law, American courts have ruled that intimate-partner sex is private, a right granted by the constitution [14,15]. Even in care settings, privacy is protected by law and is not usually questioned when the parties are competent and consenting [16].

The gradual rise in life expectancy prompts the need to house persons with NCD as well as the proliferation of facilities dedicated to their safe and humane care. While the move to a care facility for one spouse causes disruption in the life of the other, relationships continue. The affected spouse will continue to have needs for interpersonal contact and stimulation, especially when complicated by lack of mobility or opportunity to engage with the outside world. In the sexual domain, there is much variability in interest and specific activities, but there is consensus that expression of intimacy tends to improve perceived quality of life [17]. Other benefits of intimacy include nonverbal communication, the sharing of feelings, and stress reduction [18,19]. Indeed, the ability to experience sensual pleasure may persist beyond one's ability to enjoy more cognition-based activities [20] that are lost with aging. To deprive a person of pleasure on the basis of being in a care facility may induce or contribute to loneliness [21], a risk factor for depression.

A poignant example of the enduring need for intimacy involved the husband of Supreme Court Justice O'Connor. Mr. O'Connor had been admitted to a care facility with Alzheimer's disease. He developed a relationship with another woman and Justice O'Connor blessed it on the basis of compassion [22]. In a sense, she acted as his proxy without a specific document governing sexual behavior.

The idea that intimacy needs continue beyond the doorstep of a care facility was given cinematic treatment in *Away from*

Her (2006). In the film, the wife, in an early stage of NCD, enters a facility. Her husband visits and learns that she has developed a relationship with a male resident, creating emotional conflict within him. In a contrived script, the husband forms an intimate relationship with the intact wife of his wife's paramour. The plot nevertheless underscores the seriousness of the existential crisis that surrounds such a separation [19]. It is apparent that neither spouse in *Away from Her* recognized the possibility that sexual needs could be the subject of discussion or planning. The film also raises the question of how to regard the new relationship in the context of emotionally loaded concepts of marital infidelity [19] and behavioral variants of neurodegeneration (disinhibition) [23]. A woman in an earlier stage of impairment was portrayed in a later film, *Still Alice* (2014). Alice is a linguistics professor who has developed a word-finding deficit and learns that she has Alzheimer's disease. She tries valiantly to retain cognitive functioning and informs her shocked family of the diagnosis. Though it was not written into the script, one could say that a person in this stage of NCD might have retained the capacity to make her intimate wishes known in advance of transfer to a care facility. Such a scenario leads to consideration of whether a sexual advance directive (SAD) could address contingencies that would be a roadmap for partners, professionals, family, and law enforcement.

A Cautionary Tale in Middle America

In 2014, a 78-year-old man was charged with sexually assaulting his wife, who was in a nursing facility and diagnosed with Alzheimer's disease. The couple, Henry and Donna Rayhons, both widowed when they met, married in 2007. She showed evidence of cognitive decline in 2010. At the time he admitted her to the facility in 2014, Mr. Rayhons was a farmer and state legislator. Their loving relationship continued in 2014. Mrs. Rayhons' daughter was the healthcare proxy and believed that her mother should not be subjected to sexual matters. To that end, she asked that her mother be tested for cognitive functioning. Mrs. Rayhons did poorly on this general cognitive assessment, and her attending physician wrote in the medical record that she was not competent to consent to sex (though there was no specific evaluation of this capacity). This finding was also conveyed to Mr. Rayhons, who continued to visit. The patient's daughter suspected continued sexual activity and had her mother moved from a private to a semi-private room. About a week after the doctor's findings, the patient's roommate reported hearing something in the adjacent bed during one of Mr. Rayhons' visits. Several days after Mrs. Rayhons' death on August 8, 2014, her husband was charged criminally and entered a plea of not guilty. He told detectives that he and his wife were sexually active, but he later denied it, saying they merely held hands and kissed.

Mr. Rayhons was tried in 2015. Testifying for himself, he stated that nothing sexual happened at the time in question. No direct evidence of a sexual act was presented. Mr. Rayhons offered expert testimony from a physician, who testified that regions of the brain that are deeper than those that had been tested are still active after cognitive decline, permitting appreciation of sexuality. While he had not examined Mrs. Rayhons, he testified that such a person could continue to enjoy the benefits of sex, although her consent would not be verbally expressed. Mr. Rayhons was acquitted due to lack of evidence against him [24].

After the trial the State of Iowa issued guidance for administrators on the relationship between impaired persons and care facilities as related to sex [25]. For example:

“Though outcomes to sexually-related situations vary innumerable, as each is different and must be considered independently, the [Ombudsman] 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.”

While the guidance did not address whether facility administrators might act as law-enforcement agents, it placed emphasis on indicia of consent, a matter to be weighed by a team. In the guidelines that followed, the Iowa Department on Aging [26], regarded consent broadly: “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).” The policy was careful to include that legal authority may come into play. As it is, however, this type of policy attempts to resolve ordinary matters of noncoerced sexual expression within the facility, using the best indicators of the individual’s wishes at a time when formal consent may not be feasible.

Sexual Advance Directives

Returning to the legal basis for ADs in general, the idea is that, with self-determination paramount, a competent person can make medical decisions for a future in which the capacity to express wishes is lost or unknown. The operative concept here is substituted judgment: what the individual would have wanted, not what the doctor or family would do or what society or a judge might regard as being in the individual’s best interest (a lower standard). When a person chooses, through an AD, cessation of life support under defined circumstances, for example, the directives are honored and the individuals enacting the termination of life support are not liable for criminal homicide. The following excerpts from the New Jersey Supreme Court’s 1976 opinion in *Quinlan* [3] illustrate how cessation of life support is distinguished legally from homicide:

“Having concluded that there is a right of privacy that might permit termination of treatment in the circumstances of this case; we turn to consider the relationship of the exercise of that right to the criminal law. We are aware that such termination of treatment would accelerate Karen’s death. The County Prosecutor and the Attorney General maintain that there would be criminal liability for such acceleration. Under the statutes of this State, the unlawful killing of another human being is criminal homicide... We conclude that there would be no criminal homicide in the circumstances of this case. We believe, first, that the ensuing

death would not be homicide but rather expiration from existing natural causes. Secondly, even if it were to be regarded as homicide, it would not be unlawful...There is a real and in this case determinative distinction between the unlawful taking of the life of another and the ending of artificial life-support systems as a matter of self-determination...We do not question the State’s undoubted power to punish the taking of human life, but that power does not encompass individuals terminating medical treatment pursuant to their right of privacy.”

The idea of specifying, while competent, one’s wishes in relation to intimacy, once the verbal capacity is lost, is more than a thought experiment. When asked about the importance of sexuality among older adults one survey reported that 25% of persons over 75 were active at least monthly [27]. In other surveys, the majority of Swedish men aged 70 to 80 reported at least one orgasm a month [28], and the majority of respondents over 70 rated sex as important [29]. Thus, the interest in how facilities are regulated and the degree to which one’s wishes can be upheld are of considerable interest to a growing population.

While we are not lawyers, taking cues from the trajectory of self-determination case law from *Quinlan* onward, we believe that culpability for sexual activity under some circumstances can be carved out of criminal law. One legal commentator has drawn parallels between SADs and other legal instruments: *Boni-Saenz* [30] makes the point that it is possible to harmonize wishes of the former, competent self with the present, impaired self, such that there is continuity of integrity and protection from abuse. He observed that “consent is the linchpin of moral sex” and that, under ordinary circumstances, there can be no lawful sex without a competent expression of consent. Otherwise there is a conflict with criminal law. Regarding prospective decision making, *Boni-Saenz* [30] suggested that, while the law of ADs is legally solid, the Supreme Court in *Cruzan* did not guarantee a right to it. Legally, SADs are *terra incognita*. The difficulty that *Boni-Saenz* saw, on a practical level, is the analogy to contract law in the enforcement of an AD. That is, while competent, a person can have a change of mind. Therefore, it may be ambiguous whether the sex-consenting person who drafted the directive is the same person who now has cognitive decline. The spouse of the affected individual would be unlikely to win a legal argument that sexual access should be ordered on a contractual basis. Nevertheless, a combination of source documentation of the individual’s intent at the time of drafting and contextual appreciation of all risks and benefits in the present should provide reasonable outcomes. This should be accompanied by facility oversight, where applicable [30].

DISCUSSION

Desire for and enjoyment of sexual activity can outlast full cognitive capacity. Whereas sex without consent is a criminal assault, there are forms of consent that may permit a workable template for intimacy within geriatric care facilities. There is growing literature, and likely consensus, that interest in sex among older men and women is a legitimate area for discussion. Although the rules of privacy do not require regulation, as we have seen, there is a role for facilities in mediating safe and fulfilling relations.

The Hebrew Home in Riverdale (New York) has been in the avant garde of “sexual expression policy” policy since 1995 [31].

Within the laws of the state, they use a team approach to conduct a risk/benefit analysis. For situations in which both residents are cognitively intact, staffs are not expected to intervene except to provide private space and to serve as consultants. When cognition and/or judgment are questioned, or when there is a negative impact on the community, the team can intervene in the health and safety domains of all stakeholders. The residents' healthcare agents are notified to complete the information loop. The criminal case against Mr. Rayhons is an example of family bias against elder sex. There seemed to be ordinary reasons for Mr. Rayhons' visits to his wife, but the behavior was viewed by his step-daughter as unseemly, unwelcome, and a violation of Mrs. Rayhons' bodily integrity. Perhaps this example is an outlier because of the intrafamilial drama. We suspect that, at least among permissive facilities, intimacy that is truly private and does not spoil the environment of other residents proceeds unnoticed. That would be a scenario in which the facility stands back from the situation, barring indications that something is unsafe for the resident. In the Rayhons case, the physician took an extra step, at the family's prompting: trying to measure his patient's competency by using a cognitive screening test. To our knowledge, there is no valid measure of such capacity once the neurocognitive disorder is established. Nevertheless, we would not conclude that a husband and wife continuing intimate behavior constitutes sexual violence. It appears from the Iowa Department on Aging's swift response that law enforcement is not keen to prosecute simple domestic matters. The fact that one of the partners was in a facility adds a layer of scrutiny, and there is no reason to believe either that the ecology of the care home was disrupted or that Mrs. Rayhons' body was being violated. Still, it would have been better to know her wishes as expressed in advance of cognitive impairment. As we view it, there was a problem of lack of communication, which would have been resolved, had all parties convened, rather than to have the matter prosecuted.

CONCLUSIONS

The status of SADs is unknown, largely because PADs are rarely used and because ADs are private and confidential documents. Nevertheless, as we see from the Hebrew Home's policy, these matters are not left to chance, with stakeholders including the facility staff and healthcare proxies or agents. Regardless of whether SADs become standalone documents or their content incorporated into admission packets at care facilities, we believe there will be an enduring place to discuss sexuality in late life. We conclude that private, nonabusive, noncoercive sexual activity in persons with NCD is presently taking place, that it is driven by self-determination, and that it is not a form of sexual violence or elder abuse.

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