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The Sexual Revolution's **Last Frontier**: How **Silence** About Sex **Undermines Health, Well-Being**, and **Safety** in Old Age

Our ageist attitudes toward sex in old age impede quality of life and the detection and prevention of elder sexual abuse.

with age. We are a people reluctant to contemplate sex and aging together in the same thought, and even more reluctant to speak of it. Yet experience and emerging evidence indicate that such intin reticence can have significant implications for the health, rights, safety, and well-being of the large and growing older population in ways

that are just becoming clear.

In May 2011, in a colloquium sponsored by The Harry & Jeanette Weinberg Center for Elder Abuse Prevention, the Roosevelt House Public Policy Institute at Hunter College served as an historic backdrop for a daylong discussion about sex and aging, examining the subject across a spectrum—as a health, human rights, social service, criminal justice, victim assistance, and ethical issue. That horizontal analysis revealed a "perfect storm" of ageism and squeamishness about sex, resulting in a deficit of understanding and a pervasive silence about the issues that attend sexuality and aging. Consider the following examples:

• Healthcare providers infrequently offer information to or ask older patients about sex

or sexuality, thereby overlooking critical health-related data in taking histories, and missing opportunities to address issues that could enhance their patients' health, safety, and well-being.

How should we determine when a person with dementia consents to sex or physical intimacy? The answer is, it depends.

- When sexual abuse is alleged or suspected, responders rarely ask the right questions or take necessary and appropriate steps to assist victims, preserve evidence, or comply with reporting requirements. When reports are made and investigated, few cases result in prosecution, even when compelling evidence of sexual assault exists.
- Physical intimacy is rarely recognized as a core individual right that does not diminish with old age.
- The complex medical, legal, social, ethical, and practical issues that arise at the intersection of aging and incapacity—particularly cognitive incapacity—are rarely addressed, leaving practitioners and families experiencing them with little meaningful guidance or support.

This article examines how our ageism-fueled reluctance to talk about—or even acknowledge—

sex, the desire for physical intimacy, sexual identity, and sexual assault in aging can undermine the health, safety, and well-being of older people. We urgently need more data and study on these topics. In the short term, we already know enough to take some relatively simple steps that could yield meaningful change.

Sexuality and Health in Aging

Mark Lachs, M.D., co-chief, Division of Geriatrics and Gerontology, Weill Cornell Medical College, routinely asks his patients about their sexual health because "in the course of asking, I

believe I'm educating people that it's okay to talk about sex.... You have this sense that people are going to be frightened when you raise the issues, but...the

responses are more like 'Wow, this person thinks I'm a human being who is actually sexually active'" (Lachs, 2011). Notwithstanding research showing that sex remains an important part of life for most older people, and is strongly correlated with health (Lindau et al., 2007), Lachs is in a stark minority. Most physicians never raise the issue.

Study vields dramatic data In the largest ever study on sex and aging, researchers interviewed 3,005 communitydwelling people, ages 57 to 85 (1,550 women and 1,455 men), about their sexual practices, assessed their health status, and examined the correlation between the two (Lindau et al., 2007). The findings were dramatic: people who rated their health as "very good to excellent" were more likely to be sexually active than those who reported their health to be "poor or fair" (Lindau et al., 2007). The study examined correlation but not causation. Experts believe it is likely both that poor health leads to decreased sexual activity and that sexual activity leads to improved health, but we need additional research to definitively answer these questions.

Overall, the study found that while sexuality declines with age, most older adults remain sexually active and report that sex remains an

important part of life. Despite sex and intimacy being a key quality of life issue, strongly correlated with health (and often a source of "bothersome problems" with advancing age that might be susceptible to mitigation by medical intervention), only 38 percent of men and 22 percent of women reported having discussed sex with a physician since age 50 (Lindau et al., 2007). Lachs (2011) describes the infrequence with which physicians ask their older patients about sex as "shocking," saying that he is "embarrassed for my profession.... Physicians really need education in this area."

You have this sense that people are going to be frightened when age is to mention it as seldom as possible.

The good news is that this troubling finding also could be remedied: physicians simply need to treat their older patients as they treat patients of any other age; they should talk to them about sex. Failing to do so perpetuates the ageist myth that older patients are asexual. Given the clear correlation between sex and health, opening up those lines of communication could elicit real health benefits, enhance pleasure, treat "bothersome" issues, and prevent or mitigate unsafe situations—all benefits that might otherwise go unrealized.

Lindau and colleagues defined "sex" to be "any mutually voluntary activity with another person that involves sexual contact whether or not intercourse or orgasm occurs." (Had the definition encompassed masturbation, which it did not, the numbers of sexually active older people would have risen by a large margin, given that the absence of a viable partner was the most significant factor reported for lack of sexual activity.) Women were less likely than men to be in a marital or intimate relationship and less likely to be sexually active than men, with the margin increasing dramatically with age. The most frequent reason for lack of sexual activity in both genders, particularly among women (who live longer than men), was the lack of an available, willing, or able partner. Among those

not in a relationship, only 22 percent of men and 4 percent of women reported being sexually active in the previous year. In addition, 14 percent of men and I percent of women reported taking prescription or nonprescription medication or supplements to enhance sexual function in the previous twelve months. And some respondents-35 percent of women and 13 percent of men-reported that sex was "not at all important" to them.

Of the 1.198 men and 815 women in a relationship, only three men and five women reported being in a relationship with someone of the same sex, a number much lower than population estimates would indicate. Possible explanations include: the 25 percent of people who declined to participate in the study might have included disproportionate numbers of lesbian, gay, bisexual, or transgender (LGBT) respondents; or LGBT elders are less likely to identify themselves or be identified by others as such. Anecdotal reports about LGBT elders are inconsistent: while some older people come out or have same sex relationships for the first time in old age (for example, after a spouse dies), others are driven back into the closet, fearing or having experienced discrimination in facilities or by others providing aging services.

Although the study found that frequency of sex declined with age, among respondents ages 75 to 85, 54 percent of sexually active persons reported having sex at least two to three times a month, and 23 percent reported having sex once a week or more. Among sexually active elders, about half reported one bothersome sexual problem and almost a third of men and women reported two. The worse a respondent's health, the greater the number of sexual problems they reported.

The Lindau study screened out people with dementia. Thus it did not address the issues of intimacy and cognitive capacity that are often more complex, and about which we know even less. What we do know is that the desire for physical intimacy remains critical for many older people, regardless of cognitive capacity.

Interest in physical intimacy among people with dementia is variably manifested: they may be less interested in sex; more interested; less inhibited; or interested in new or different types of sexual activity than before. The hyper-sexuality that accompanies some dementias is underreported and under-addressed, but often causes serious and confusing behavioral problems both at home and in residential facilities. It poses challenges for the person with dementia as well as his or her sexual partners (consensual or not), family members, caregivers, and, in facility settings, often other residents.

Elder Sexual Assault

Elder sexual assault, although largely hidden. can take many forms and occur in any setting, such as in community or in a facility.

The four case examples on page 46 illustrate a troubling pattern: again and again, professionals who might have responded with care and concern failed to do so. Why? They didn't believe the older person who reported a sexual assault, or respond adequately when a sexual assault was alleged or suspected. They didn't do the necessary care planning to assure the safety of others housed in a facility with someone known to be sexually aggressive. They didn't identify injuries to the rectum and genitalia as strong indicators of sexual assault. And they didn't believe that a

Physical intimacy should be on the list of issues to be addressed in care planning.

person with dementia could accurately report sexual assault and suffer the consequences of trauma from a sexual assault (despite the finding of Burgess and colleagues [2008] that there was no significant difference between elders with and without dementia in post-sexual abuse behavioral symptoms of distress).

Our failure to take elder sexual assault seriously is fueled partially by two erroneous beliefs: that older people are asexual and that sexual assault constitutes sexual activity (assault is more about power than about sex).

Cases of Sexual Assault

The following four case examples illustrate some of the myriad challenges in properly addressing the issue of elder sexual assault.

- 1. The suitor who wooed a widow at the senior center seemed so charming until after the wedding, when he became sexually abusive. When she told her doctor that her husband "hurts me sexually," the physician gave her a vaginal cream. When she persisted and said, "He makes me do things I don't want to do," the doctor said, "Just tell him no." She thus endured several months of additional abuse until she had another opportunity to seek help (Ramsey-Klawsnik, 2003). This is another manifestation of the potential health risks when physicians refuse or do not know how to discuss sexual matters with their patients, and are ignorant about sexual abuse in later life.
- 2. A 65-year-old man with profound disabilities had bruised genitalia and was so brutally raped with an object by a male care attendant that he required surgery to repair injuries to his rectum. Adult Protective Services (APS) substantiated the case only for physical but not for sexual abuse. The aide admitted that he had "roughed up" the resident when he wouldn't cooperate during showering. When questioned, APS said it did not have sufficient proof of sexual assault to "substantiate." The police held the same view and arrested the perpetrator only for physical assault (Ramsey-Klawsnik et al., 2008). This case illustrates the need for additional research and education regarding sexual assault in later life in general and specifically about forensic markers (such as a torn rectum and bruised genitalia) of elder sexual assault. Such injuries are well-established markers of sexual assault when it comes to younger victims.
- 3. Another scenario involves the sexual assault of one resident of a long-term-care facility by another resident. In some cases of resident-to-resident sexual assault, one or both residents have dementia. In one case, a woman resident reported that while in the dining room, a male resident had grabbed and roughly pinched her breast. Although investigating APS workers called the woman "highly credible," facility staff put a note in her medical record: "Makes false allegations of sexual abuse. Monitor carefully."
- 4. In another case, there was incontrovertible evidence (eyewitness evidence and semen) of a demented male resident with a long history of hyper-sexual behavior having assaulted a woman with dementia within hours of her admission to the facility and again subsequently. She never walked again, lost weight, and died soon thereafter. Instead of examination by a sexual assault nurse examiner, the only evaluation consisted of a facility nurse using a flashlight to examine the woman's condition. Although she had no history of dementia-related sexual behavior, a psychiatrist wrote in her record, "She wanders into other people's rooms seeking warmth." And when a physician for the family concluded that she had suffered from post-traumatic stress disorder (PTSD) as a result of the sexual assaults, a lawyer for the facility claimed, "A person with dementia has memory loss, so can't remember an incident to have PTSD."

The insidious, multifaceted impact of ageism thus permeates our response to matters involving sex and aging, impeding a sensible, thoughtful, humane, legal, and ethical response to elder sexual assault.

Research Puts Sexual Abuse into Context

The anecdotes recounted on page 46 are beginning to be framed and put into context by recent research that has examined the dimensions of the problem and the characteristics of perpetrators.

Two prevalence studies

Two recent elder abuse prevalence studies, conducted via phone survey, elicited information about all types of elder abuse, neglect, and exploitation, including elder sexual abuse. Notably, these two prevalence studies exclude the most vulnerable elders: those unable to answer the phone or who do not have a phone; those scared to answer the phone; those with dementia; or those living in a facility. The emerging prevalence data are as follows:

- The New York State Elder Abuse Prevalence study found that 7.6 percent of respondents ages 60-plus were abused, neglected, or exploited, and that elder abuse remains largely hidden: for every one case that came to light, another 23.5 did not (Lifespan of Greater Rochester et al., 2011). (The New York prevalence study evaluated all types of elder abuse, including, but not limited to, sexual assault.)
- The Medical University of South Carolina national elder abuse prevalence study in 2010 found that 0.8 percent of women and 0.3 percent of men ages 60-plus had been sexually assaulted, (Acierno et al., 2010), although the sample size was too small to produce statistically reliable results.

Dearth of study focus on sexual assault and dementia No study has focused specifically on the prevalence of sexual assault of older people with dementia. But, as illustrated in the case examples on page 46, and by several studies, there is reason for serious concern here, too. Ramsey-Klawsnik et al. (2008) found that among 124 elders residing in healthcare facilities who were reported to state authorities as suspected sexual abuse victims, 64 percent had dementia. In a study of 129 dyads (pairs including a person with dementia and a family caregiver), 47 percent of people with dementia who were cared for at home by caregivers were abused or neglected by those caregivers (Wiglesworth et al., 2010). (The conclusion of mistreatment was usually based on the caregivers' own admissions, but this study did not include sexual assault or financial exploitation.)

In addition, studies of sexual assault of younger people with cognitive and developmental disabilities consistently indicate that at least half or more have been sexually victimized (Johnson and Sigler, 2000; Young et al., 1997; Sobsey, 1994). We need more research to gain a better understanding of the prevalence and nature of—and how to prevent sexual abuse of—elders with cognitive impairment. In the meantime, even absent such research, it seems reasonable to conclude that cognitive incapacity in old age presents a significant risk factor for sexual assault.

Data on sexual abuse in healthcare facilities Ramsey-Klawsnik and colleagues (2008) examined the characteristics of 119 individuals alleged to have sexually assaulted an elderly resident of a healthcare facility in which the incident was reported to APS and-or to other state authorities. Most of the alleged sexual abusers were either facility employees (43 percent) or other residents (41 percent), and the rest were partners, other family members, visitors to the facility, or those who had unknown relationships to the victims. Investigations by Adult Protective Services or state regulatory staff substantiated sexual assault in only thirty-two of the 119 allegations. A statistically significant difference in substantiation rates emerged for accused facility employees and residents. Only 4 percent of cases alleged to have been perpetrated by staff were substantiated, versus 52 percent of cases alleged to have been

perpetrated by another resident. Ramsey-Klawsnik and colleagues hypothesize that the reason for the disparity is that "[r]esident perpetrators may have been less able than employee perpetrators to effectively conceal evidence of their sexual assaults." It's not clear whether there was a difference in the degree to which the facility or others cooperated in the investigation where the accused was a resident versus a staff member.

Not a single one of the thirty-two confirmed cases—let alone the 119 alleged cases—resulted in arrest or prosecution of the alleged perpetrator, even where the evidence included positive rape kits and statements by victims, and eyewitnesses to the alleged crime (Ramsey-Klawsnik et al., 2008). These findings echo the results in the case examples on page 46, exhibiting a similar disbelief, mishandling, and ignoring of allegations of elder sexual assault. Collectively, they point to an urgent need for additional guidance for and training of law enforcement officers, prosecutors, state officials (including regulators), APS workers, and facility staff about the handling of elder sexual assault matters.

In practice, APS and state regulators' standards for "substantiating" or "confirming" a case vary substantially from state to state, locale to locale, and even employee to employee (Kesler-West, Wiglesworth, and Mosqueda, 2008). Such professionals rarely have training in elder sexual assault, in how to collect forensic evidence, or in how to conduct victim and suspect interviews. They rarely have access to expert consultants, nor do they have subpoena authority or grand juries to assist them in their investigations. In addition, APS in particular is dramatically underfunded, lacks training, uniform guidance, or practices. These factors often undermine its ability to fulfill its mission.

Identifying and pursuing the perpetrators
There is much that law enforcement and
prosecutors have learned about sexual assault
cases, based on decades of research, training,
and practice relating to the sexual assault of
younger victims. Why then are elder sexual

assault cases so rarely identified or pursued? Why are lessons from other arenas not imported? It would appear ageist assumptions about older people and sex (again) are to blame—responders can't bring themselves to believe that anyone could possibly want to sexually assault an older person. The problem is compounded by lack of professional training in this area and assumptions that older people—especially those with dementia—are somehow less human, and less entitled to our empathy and our efforts to identify and redress their sexual assault.

A qualitative study of 100 cases of sexual assault of older people living at home with family members (Ramsey-Klawsnik, 2003) found that some sexually abusive spouses viewed their wives as their "sexual property." Many elders sexually assaulted by children or grandchildren experienced powerful, ambivalent feelings toward their abusers; this complicated their trauma response and made it difficult for them to accept intervention.

Older people living in private residences are more isolated and less likely to be identified or assisted. But occasionally, responders get it right. During a homecare nurse's routine monthly home visit to a woman being cared for by her son-in-law (after her daughter had died), the nurse noted the woman's high blood pressure and racing pulse. She asked if something was wrong. The woman began, reluctantly, to describe her plight, saying that her son-in-law took photographs of her naked. The nurse took the time to listen carefully, asking respectful, astute, and open-ended follow-up questions. Answers to more questions revealed that the son-in-law also sexually assaulted the woman under the guise of "checking" her. The nurse worked with the woman to make a report to APS and the police. APS helped her find temporary shelter, the police got a search warrant and found the photographs, and the son-in-law was prosecuted (Ramsey-Klawsnik, 2003).

The proper handling of cases depends on each potential responder—representing a link in the chain—doing the right thing. The nurse, despite her busy schedule, took the time to ask

Sexual Rights and Dementia: Two Scenarios

Scenario 1: Interfering with intimacy: a balancing act

A nursing home resident with dementia who no longer recognizes her husband of 50-plus years becomes involved and intimate with a widower who lives at the same facility and also has dementia. The woman's husband and children are supportive of her new relationship—it has enhanced her well-being. But the man's daughter, who also is his guardian, insists that the facility staff break up the relationship or she will sue and move him to another facility. The daughter is adamant: Dad was devoutly religious, dedicated to the memory of his wife, and would be horrified and ashamed if he knew that she had sanctioned an extra-marital relationship. The facility staff plead his rights with the daughter, pointing to prior experience as evidence that splitting up the couple could lead to depression, deterioration of their health, and hasten their mortality.

There is little guidance for family members or staff about how to balance the competing individual rights, ethical considerations, and legal requirements in this case. While the father's choice is clear, the legal question is what weight should be given to his daughter's views, given her legal status as his guardian, and her claim that her position reflects her father's wishes when he was cognitively intact? The broader question is what, if any, weight should be given to the views of family members in such situations, regardless of their legal standing? The roles of facility protocols, staff, and care planning similarly are critical in respecting the decisions residents with dementia are able to make regarding physical intimacy, but not using "respect for autonomy" to justify lack of vigilance that results in sexual assault.

Scenario 2: Is it sexual expression or sexual abuse?

Even more complex scenarios are raised when it is unclear whether a particular encounter is an expression of sexual rights or abuse. Such was the case where an 87-year-old woman with advanced dementia was found by a nursing home aide in bed, underwear partially down, while her gentleman visitor, in his early 50s, hastily pulled up his pants and washed his hands. When interviewed, the woman said that she enjoyed having him visit and called him her boyfriend. She said that he told her that she was beautiful and kissed her, but she claimed that she would never have sex with him. She denied having had any other sexual contact, but the rape kit revealed evidence of intercourse.

The staff decided, likely correctly, that the man was taking advantage of her. But she might have viewed his visits differently and would not be the first person to have an unrealistically rosy perception of a suitor's intentions. But how should the staff discern her state of mind? Did she enjoy having sex but was reluctant to acknowledge this? Was she traumatized by nonconsensual sex but reluctant to talk about it? Was she so lonely that she was willing to subject herself to opportunistic intimacy that she otherwise would have refused? Did she really not know that she had engaged in intercourse? What duty should be placed on a partner who has capacity to determine whether his or her putative sexual partner who lacks capacity has provided true (and legal) consent, especially if he or she appeared to willingly engage in sex?

questions and really listen to the woman's responses. The police and prosecutors responded promptly and took action. Unfortunately, such responses appear to be more the exception than the rule.

The Right to Retain Sexual Expression

How should we determine when a person with dementia consents to sex or physical intimacy? The answer is, it depends. Such determinations often require a careful balancing of autonomy and safety. Capacity is not a bright-line phenomenon; it exists along a continuum. In different stages of the disease, dementia might incapacitate certain types of decision making, but not others. A person might no longer be able to make complex financial decisions, but may retain the capacity to decide if, with whom, when, and where to engage in physical intimacy.

The clinical complexities inherent in determining if an older adult with impaired capacity has the ability to grant informed consent to sexual activity is discussed in a handbook produced jointly by the American Bar Association and the American Psychological Association (2008). Page sixty-two of this handbook points out the difficulty, as follows: "There are no universally accepted criterion for capacity to consent to sexual relations." But there have been some attempts to address and provide guidance regarding the rights of residents of long-termcare facilities to engage in intimate relationships if they wish to do so (Center for Practical Bioethics, 2006; Center on Aging, Kansas State University, 2003).

It is simple to proclaim the human and individual right of a person with dementia to engage in consensual physical intimacy, to the extent consent can truly be ascertained. But these scenarios raise difficult issues. To make those rights realizable will require no small amount of guidance and grappling with all manner of issues. Often, cognitive incapacity results in the transfer of legal decisionmaking authority to an adult child or other family member who may have strong views about what is and is not appropriate.

We would likely agree that dementia does not confer an absolute prohibition against sex. But how should a facility balance its duty to protect residents from assault with its duty to honor residents' choices about physical intimacy? In Scenario 2 on page 49, the prosecutor declined to press charges, and the facility banned the man from visiting. But is that what the woman would want?

We have not yet done the simple things—to ask older people about physical intimacy and respond properly to clear allegations of sexual assault, let alone developed an understanding of and ways to navigate the much more complex issues relating to consent and cognitive capacity. Just beginning a broader conversation that acknowledges the issues and does not discount the needs, desires, and rights of people with dementia for intimacy would represent real progress.

A Path Toward Meaningful Action

Our steadfast refusal to think of older people as sexually sentient beings is ageist. It is expressed explicitly when we refuse to ask about sexual health and refuse to believe or respond to allegations of sexual victimization of elders. And it is expressed implicitly by our failure to demand policies, programs, procedures, and guidance to promote healthy sexuality and prevent victimization in old age.

Ageism is so entrenched in our culture that it presents a profound opponent to change. But progress is possible. At a minimum, we can begin to have conversations about these very complex issues. In addition, the following are relatively simple steps that could help us begin to address these issues in a more meaningful way:

- Healthcare providers should talk to their older patients about sex; and physical intimacy should be on the list of issues to be addressed in care planning.
- Healthcare providers should have procedures for handling the sexual hyperactivity that attends some dementias in order to protect both potential victims and the person exhibiting such behavior.

- Potential responders (such as police officers, health and social service providers, APS, long-term-care ombudsmen, state officials, victim advocates, senior centers, aging services network workers, and others) should know how to handle allegations of sexual assault in ways that protect and respect victims, preserve evidence, and assure proper reporting and response.
- Law enforcement officials and prosecutors should receive training on how to identify, respond to, and pursue allegations and cases of elder sexual assault; they need better tools for learning how to proceed in the face of suspected cognitive deficits of either potential victims or alleged perpetrators.
- Professionals working in the field of aging and those working in domestic violence and sexual assault fields should share knowledge and resources to better respond to the needs of older victims of sexual assault.
- Medical and legal ethicists, along with gerontology experts, policy makers, and practitioners, should begin to discuss and provide guidance and support for those who encounter the complex issues that arise at the intersection of sex, aging, and diminished capacity.
- Researchers should devote greater attention to these complex issues (including improving our ability to assess capacity for sexual contact), and funders (federal and philanthropic) should provide resources to support such research.

For now, our primary response to sexuality in old age is to mention it as seldom as possible. The result is that that we're missing countless opportunities to prevent suffering and enhance older adults' well-being.

The time has come to begin engaging these issues. If we do not, we may find that ageism has eroded the very rights we worked so hard to realize: the right to make choices, to be believed, to be free of violence, and to recognize sex and sexuality as integral to health, identity, and well-being, not just in youth, but at every stage of life.

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