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Invited Perspective

Sexuality and the Human Rights of Persons With Dementia

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ABSTRACT

We explore barriers to enjoyment of human rights to sexuality of persons with dementia and remedies for addressing these. Enjoyment of sexuality is contingent upon actualization of rights to dignity, autonomy, respect for will and preferences, abuse safeguarding and equitable access to highest standards of sexual health. Persons with dementia living at home or in care face systemic barriers to enjoyment of sexuality fueled by ageism, apathy and ignorance, compounded by complex legal barriers in relation to consent. Such challenges can be tackled with awareness raising and education of care staff, families and physicians, including training for capacity assessment with dimensional, non-categorical conceptualization of capacity, leaving room for supported decision-making. These measures, together with strengthened legislative and human rights frameworks to cater to the specific needs of older people, may allow people to live well with dementia and exercise their human rights to enjoy sexuality in a safe and lawful manner. (Am J Geriatr Psychiatry 2021; 29:1021–1026)

Highlights

- We explore barriers to enjoyment of human rights to sexuality of persons with dementia and remedies for addressing these.

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- Persons with dementia living at home or in care face systemic barriers to enjoyment of sexuality fueled by ageism, apathy and ignorance, compounded by complex legal barriers relating to consent. This can be tackled with awareness raising and education of care staff, families and physicians, including training for capacity assessment using a dimensional, noncategorical conceptualization of capacity, leaving room for supported decision-making.
- Stakeholder education strengthened by legislative and human rights frameworks catering to the specific needs of older people may allow people to exercise their human rights to enjoy sexuality in a safe and lawful manner.

INTRODUCTION

Sexuality is a "central aspect of being human throughout life encompass [ing] sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction."[1] As conceptualized, the positive effects of sexuality for the physical and mental wellbeing of older people are undisputed.[2] However, its fulfillment is contingent upon actualization of a wide range of human rights, including but not limited to: 1) dignity; 2) autonomy; 3) freedom of opinion, expression and respect for will, and preferences; 4) support for decision-making; 5) equality and nondiscrimination; 6) freedom from abuse and inhumane or degrading treatment; 7) privacy; and 8) access to the highest attainable standard of sexual health.[1,3,4] The right to a sexual life where there is true consent and mutual desire has been acknowledged by the courts as a "fundamental human right."[5]

All persons enjoy these rights, regardless of age or disability, as enshrined in several human rights frameworks.[4,6] The Convention on Rights of Persons with Disabilities makes clear that this is irrespective of disability.[4] However, proper enjoyment of the rights to sexuality of persons with dementia[7] has been prevented by a range of ageist and mentalist stereotypes.[8–10] In pursuit of the public good of ensuring that sexual activity is consensual, civil and criminal laws often intrude further on enjoyment of sexuality when one (or both) partners have lost the capacity to consent to sexual activity.[11] Further challenges arise in long-term care, where privacy is abolished,[12] and others—care staff, family members, or physicians—make decisions about the sexuality of persons with dementia. These challenges arise in the context of complex interactions between dementia and sexuality, including changes in expression and perception of sexuality and intimacy needs, as well as frequency of and satisfaction with sexual activity.[13–16]

The approach to sexual expression of people with dementia needs to be founded in human rights frameworks.[3] In this paper, we explore existing barriers to full enjoyment of human rights to sexuality of persons with dementia and offer hope with potential remedies.

BARRIERS TO ENJOYMENT OF HUMAN RIGHTS TO SEXUALITY

In care settings, the expression of sexuality for persons with dementia is mediated by care staff at the frontline, facility policies [17] and families. Not surprisingly, all struggle in this area.[18,19] Inadequate staff education and institutional policy do nothing to dispel ageism-fueled indifference to sexual needs of older people, abhorrence of intimacy between older people, and stereotypes of older people as asexual.[9,10] Frequently, the focus is on extinguishing sexual behaviors (usually with psychotropic medications), rather than understanding them as communication-impaired or disinhibited expressions of normal needs.[3,14,20] This is compounded by perception of families (often adult children) that they must be kept informed and involved in decision-making regarding their relative's sexual behaviours.[18] Relatives and care staff often feel that is their responsibility (or that of the care home) to decide on behalf of a person with dementia that sexual expression should be terminated.[19] Couples including a partner with dementia face a range of emotional and practical facility barriers to meeting their sexuality needs.[21] By failing to support at best, or at worst frankly obstructing

expression of sexuality, facilities miss opportunities for promotion of autonomy, supported decision-making, and respect for will and preferences, and may be in breach of human rights legislation or frameworks.

Much of the research is focused on care settings where lack of privacy exposes expression of sexuality. However, for those living at home, expression of sexuality can be equally challenging. Individuals may struggle due to limited free mobility and opportunities to engage with others,[22] while couples struggle with adapting to the changes in sexuality associated with dementia.[13,23,24] These invisible issues often fail to come under the radar of healthcare professionals.

In the legal sphere, barriers to the enjoyment of human rights to sexuality exist in criminal and civil spheres. These barriers have (normally) not been erected deliberately but rather arise in consequence of the pursuit of other goals, most obviously the requirement for contemporaneous consent to sexual activity, common to many jurisdictions.[11] Consequently, sexual offences can be committed, even by spouses, where one party is considered or deemed not to have consented to the sexual act due to lack of capacity. In civil spheres, courts have pre-emptively prohibited sexual activity and endorsed restrictions on access and supervision.[11]

At the interface of legal and clinical spheres in most jurisdictions lies capacity assessment. Although in many jurisdictions, it is the judge who makes the ultimate determination as to the relevant capacity,[5] courts still rely on expert evidence. Moreover, before these cases reach the courts (and sometimes to divert cases from the courts), it is the role of clinician to assesses capacity. However, physician knowledge and assessments of capacity have been shown to be inconsistent, subjective and often suboptimal.[25–27] In the area of sexuality, physicians lack of knowledge and awareness of sexuality and sexual problems in older people compounds this.[28-29] A person-centered rights approach to assessment requires expertise to ensure that human rights of dignity, autonomy, opportunities for supported decision-making and safeguarding against abuse are respected.[30] In this way, "the rights of the incapacitous"[5] are in the hands of capacity assessors and their approach to assessment. This is further compounded by the categorical "absolutization"[7] of capacity for sexuality as being either absent or present. Given legal consequences of a determination of lack of capacity and the consequences for autonomy, a dimensional conceptualization of capacity for sexuality would far better serve the human rights of people with dementia, to be discussed below.

SUPPORTING HUMAN RIGHTS TO SEXUALITY

In long term care, systemic barriers to enjoyment of these rights need to, and can be, dismantled by tackling ageism and ignorance with awareness raising and education. Resources[31,32] and tools such as the Sexuality assessment tool (SexAT) [33] have been purposefully developed for this. For care facilities, SexAT allows self-audit of policies that promote resident rights for privacy and assistance with regards to sexual expression, as well as provision of staff and family support, education and training. Families who find the sexual behavior of their relatives challenging and emotionally painful[18] need education and support. Staff need support and training to deal with the wide variety of clinical situations involving sexuality with which they are presented.[34] Finding thoughtful and pragmatic solutions require staff to be person-centered and flexible in both advocacy and safeguarding roles, which need to be dynamic and responsive to changing clinical circumstances.[35] While at times staff may actively assist a resident in maintaining a satisfying sex life, at others they may be obliged to discourage sexual behaviours.[35]

Receiving a diagnosis of dementia does not signal the end of sexuality regardless of the living circumstances of the person. The sexual needs of the individual or the couple are an essential part of psychosocial care and cannot be neglected by health professionals. Furthermore, moving into a care home need not and should not signal the end of intimate relationships.[32] Providers have duties to support and facilitate existing intimate relationships by recognizing the needs of couples[21] and this extends to promotion of Lesbian Gay Bisexual Transgender Plus inclusive practices.[36] Equally important, but far more complex, is support (when required) for new intimate relationships in care settings, which require nuanced, individualized approaches depending on each couple and the presence of existing partners. Many of these cases are complicated by existing family relationships involving adult children and blended

families, sometimes acting out former conflicts.[3] Posited solutions for promoting autonomy, privacy and dignity include an acknowledgment that spouses have a greater need, role and right to be involved in decision-making regarding sexuality than adult children, with whom information can be shared on a ''need to know'' basis.[20]

Knowing when to leave alone and when to intervene is a huge challenge for all health professionals. In Table 1, we provide a suggested approach to a sexual relationship involving at least one cognitively impaired individual.

TABLE 1. Human Rights-Driven Approach to Sexuality in Dementia: A Guide for Health Professionals[3,37,38]

1 What are the systemic and family factors contributing to the referral?

- a Is there good reason to rebut the presumption of capacity for all adults? Does the sexual expression warrant assessment and intrusion on the person's privacy and rights due to harm or abuse?
- b Do family and staff understand sexuality and the needs and rights of the person?

2 If assessment warranted, consider each partner in the relationship in regards to:

- a Causes of behavior: neurodegenerative/ cognitive; needs based (e.g., intimacy, sexuality) and drives (disinhibition, aggression);
- b Capacity (Do they understand the nature and consequences of sex)
  - i Nature:-
    - 1 Do they understand what sex is?
    - 2 Do they understand who the partner is?
  - ii Consequences
    - 1 Do they understand what the consequences of sexual activity are, if there are any (e.g. genital trauma/itch etc.)?
    - 2 Can they advocate for their interests, say "No" when they want to;
    - 3 Can they understand and respond appropriately when the partner says "No"
- c Harm, risk or abuse
  - i Is there inequity in age, cognition or power"?
  - ii Is there evidence of protest, resistance or coercion? NB. Accession or assent is NOT consent.
  - iii Is there evidence of pleasure?
  - iv Is there evidence of harm or injury: physical (e.g. bruising, bite marks) or psychological. Consider in nonverbal, dysphasic or apathetic patients other signs such as behavioral change after conjugal visits, increased agitation, behavioral psychological symptoms of dementia, sleep or appetite disturbance?

3 To intervene or not: Use positive risk management, or risk enablement approach.[39] Use nonpharmacological measures involving needs satisfaction, access and distraction first where possible. Reserve medication use for harm and intractable predatory behavior.

Any clinician applying this guide must have regard to the law in their own jurisdiction.

A dimensional, rather than categorical conceptualization of capacity for sexuality leaves room for supported decision-making, consistent with Article 12 Convention on Rights of Persons with Disabilities. In practical terms, this means in the presence of impaired (i.e. not absent) capacity and the absence of harm or abuse, facilitation of decision-making and specifically, facilitation of will and preferences. Residents in long term care facilities can be supported to practice sex safely and comfortably. This must include support for dignity and privacy, with a space for intimacy without disturbance, [40] but additionally might include support for sexual expression such as purchase of intimate clothing, lubricants, sex toys, condoms, and access to sex workers.[41]

All of these steps can and should be taken within current legal frameworks. However, some steps would require the amendment of those frameworks to address the fact that there will be some who cannot, even with support, give contemporaneous consent. In the context of those with dementia who have, but may be at risk of losing the ability to give that consent, one proposal would be allow for the execution of Advance Decisions on Intimacy (ADI).[11,42] Using the concept of precedent autonomy (former self deciding for future self) and modelled on advance decisions to refuse medical treatment, an ADI may empower individuals to make decisions about how they would wish to express their sexuality at a future time when they lose capacity to consent to such.[11]

CONCLUSION

Notwithstanding the challenges, there is no place for nihilism in human rights advocacy for promoting enjoyment of sexuality of people with dementia. With awareness raising, education and strengthening legislative and human rights frameworks to cater for the specific needs of older people,[8,11] key stakeholders can be empowered to lawfully uphold the human rights of persons with dementia. Persons with dementia should be empowered to live well with dementia and exercise human rights to enjoy sexuality in a safe and lawful manner.

AUTHORS' CONTRIBUTION

All authors contributed to the conceptualization, writing, and editing of the paper.

DISCLOSURES

None to declare.

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