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Addressing Sexuality in Dementia: A Challenge for Healthcare Providers

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Abstract

Human sexuality is increasingly recognized as an important aspect of health and quality of life. Regardless of age and health status, the need for intimacy, affectionate relationship and sexual satisfaction does not fade away. Dementia has a major impact on various dimensions of sexuality. Normal and inappropriate sexual behaviours, as well as the need for physical and emotional closeness are distressing for patients with dementia as well as their spouses, family members, caregivers and healthcare providers. Management of these sexual expressions demands a comprehensive evaluation, and can be treated by non-pharmacological and pharmacological interventions. When sexual expressions are displayed, multidisciplinary professional collaboration may contribute to better assessment, lead to better intervention and may reduce stress among people with dementia as well as their families and healthcare providers.

Keywords: Dementia; Inappropriate sexual behavior; ISB; Hypersexual behavior; Management; Masturbation; Sexual behavior and Sexuality

Introduction

Sexuality is a broad multi-dimensional construct and a key aspect of personality and behaviour. Sexuality encompasses basic human needs for love, affection, relationship, intimacy and explicit sexual activity. Being old or having acquired cognitive or physical impairment does not erase these human needs. A study among 3005 US elders aged 57-85 indicates that about half of them, and about one third of those aged 75-85 are sexually active [1]. Many residents in aged care facilities, both with and without dementia, feel that sexuality "still matters" [2]. The World Health Organization declares that sexual health should be inherent part of health care [3]. Recent literature discuss expressions of sexuality in long term care (LTC) (including people with dementia) in relation to the legal, ethical and policy challenges [4,5], further emphasizing the importance of raising staff's awareness and understanding in this realm. By embracinga broad perspective of human sexuality, health care professionals can take an active role in helping older clients with respect to the expression of their sexuality in later years, especially when one has dementia. However, studies have indicated that physicians, nurses and other health care providers rarely address sexual issues proactively [6]. Sexuality of people with dementia is often prohibited in LTC, because of the underlying and dominant presumption that someone with dementia lacks decision making capacity, and sexual expressions are considered harmful for the residents and the facility. This short commentary is designed to increase awareness to the variety of intimate and sexual manifestations displayed by people with dementia, and to describe management options.

Intimate and sexual expressions in dementia

Sexuality is far more than having intercourse. Sexual expressions in dementia exist on a continuum, ranging from a need for closeness (holding or touching) to erotic activity aimed at achieving sexual pleasure, from a natural sexual desire to inappropriate sexual demands, or even disinhibited hypersexual behaviour. This article will focus on three common sexual expressions reported among people with dementia: the search for physical closeness, masturbation and inappropriate sexual behavior.

Search for physical closeness: Patients with dementia of both genders prefer non-intercourse intimate closeness (kissing, hugging, cuddling, etc) and most of them (82.5%) respond positively to physical touch [7]. Patients as well as their partners experience reduced opportunities for tactile expressions. Moreover, when a person with dementia initiates physical contact with a caregiver or a staff member, it might be erroneously interpreted as an intention to have sex. Consequently, the need to touch and be touched is ignored. Studies have shown that supportive touch can have good outcomes in a number of different realms. Woods et al. [8] compared the effect of therapeutic touch in a randomized double-blind three-group experimental study of 57 residents with dementia, aged 67 to 93. The authors found that therapeutic touch could be considered as a non-pharmacological intervention to decrease behavioral symptoms of dementia, specifically manual manipulation (restlessness) coupled with stress and vocalization.

Masturbation: This is a common satisfying self-stimulating activity among people of all ages. An Australian study of 20094 men and women aged 16-69 found that 72% of the men and 42% of the women had masturbated in the past year [9]. The auto erotic activities were both substitutes for partnered sex and additional sources of pleasure for people with sexual partners. In another study half of the men aged 60-69 and 26.7% of married men over 70 had masturbated in the last 3 months [10]. Self-stimulation was the most frequent sexual activity among women aged 75 to 85, most of them did not have a partner [1]. Privacy is essential for masturbation, but is frequently reduced, particularly in LTC [11]. Many facilities lack private space and frequently residents share a room with others. When they are "caught" during masturbation, even in their own room, their behaviour might be

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regarded as inappropriate or hypersexual. Unsurprisingly, masturbation is often reported as one of the inappropriate public behaviours in dementia [12], and there is little evidence about this behaviour as a healthy activity in the elderly.

Inappropriate Sexual Behaviour (ISB): ISB is one of the challenging neuropsychiatric behaviours in dementia, with reported frequency of 2.2% to 25% [13,14]. The neurobiological basis of this inappropriate comportment is still vaguely understood and may reflect a prevailing behaviour associated with the dementia or may occur in relative isolation [15]. ISB occurs significantly less than other disturbing behaviours in dementia (e.g. aggression and agitation). Nevertheless it has been described as considerably embarrassing and distressing for caregivers and families as well as health professionals (mostly nurses), who find it difficult to handle [13,16,17]. When confronting with ISB, it is essential to make distinction between two main types of sexual behaviour: normal sexual behaviour and sexually disinhibited behaviour. The first is a sexual behaviour misplaced in social context, inappropriate location or time (e.g. masturbating or undressing in public areas) [18]. Due to confusion and misidentification, the sexual behaviour may be, sometimes, aimed at a wrong person (e.g. kissing or touching a staff member or a caregiver). It is important to point out, that spouses report on feelings of distress following sexual overtures from partners who no longer recognize them [19]. The second type is sexually disinhibited behaviour, which is part of the general behavioural disinhibition in dementia (e.g. lewd language, exhibitionism, repeating attempts to have sex, aggressive sexual demands) [20,21].

Management of sexuality concerns in dementia

Only few studies address the management of sexuality in dementia [2,15]. Evaluating patient's needs, with respect to sexuality in its multidimensional construct, may be the first step to create a change. This can be easily achieved by encouraging healthcare professionals to regularly discuss sexual dilemma and issues. Open communication may assist health teams in consolidating adequate policies and procedures. The Sexuality Assessment Tool (Sex AT), a self-report tool for residential aged care facilities, can be useful for these purposes [2]. Special emphasis should be given to providing opportunities for tactile stimulations, e.g. using live pets or soft dolls, or introducing face or head massage [8,15]. In couples troubled with dementia, intimate non-intercourse touch may increase feelings of closeness and happiness.

Sexual consent is a complicated construct, and assessment of consent capacity should be taken into consideration [5,22]. Assessment should carefully challenge the presumption that someone with dementia lacks decision making capacity. A typical case might involve two residents desiring erotic touch or sexual activity, with at least one of the residents having a questionable capacity. Preliminary information, including history of sexual behavior, past inappropriate sexual activity or being abused, should be gathered through discussions with staff and family (when relevant).

Management of ISBs commences with a careful assessment. Acute emergence of any behavioural disturbance in dementia, including ISB, should be carefully evaluated to rule out an underling medical condition (e.g. delirium) [23]. In cases of persistent disruptive and distressing ISBs, non-pharmacologically approaches should be applied primarily. If not successful, pharmacological therapies can be tailored to the individual patient, taking into consideration the underlying neuropathology of the specific behaviour [15].

Non-pharmacological interventions need to be adjusted to the individual case, and may include removal of precipitating factors and distraction strategies. Multidisciplinary team collaboration might be effective in reducing dementia related sexual behaviours. For example, in case of obscene sex language or aggressive attempts to have sex, Bronner et al. [15] suggest the following interventions: (1) Decreasing stress; (2) Separating the patient from the other person that appears to be the trigger for ISB; (3) Firmly responding "That is not acceptable!"; (4) Using distraction techniques (walking outside, playing a new game etc.); (5) Leaving the room for a few seconds, to break the cycle of the behaviour; and (6) Finding alternatives to relieve sexual urges (e.g. privacy for masturbation).

Conclusion

Despite the sensitivity and complexity of sexual expressions in people with dementia, clinical experience confirms that this issue is amendable. Staff collaboration, open communication and interdisciplinary assessment enable optimal management of intimate, sexual and hypersexual behaviors. Future research on pharmacological and non-pharmacological interventions is needed, addressing the needs of persons with dementia, their spouses, the caregivers and the healthcare providers.

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