The Expression of Intimacy and Sexuality in Persons With Dementia

Migita D’cruz1, Chittaranjan Andrade2, and T. S. Sathyanarayana Rao3

Abstract

Sexuality in dementia is infrequently addressed. Dementia is characterized by a progressive deterioration in all domains of functioning, including loss of sexual function. However, the diagnosis of dementia does not mean an immediate or complete cessation of sexuality in the person, or a loss of the ability to consent to sexual activity with a partner.

A discussion of sexuality in dementia occurs infrequently in clinical care for several reasons. These include (a) a discomfort in discussing sexuality in older adults, (b) the fear of causing social or cultural offense, and (c) the assumption that the cessation of the reproductive period implies the end of sexual life in older adults. There is also a tendency to focus on the preservation of cognition and independence, with relative neglect of the need for physical and emotional intimacy or quality of life.

Patients with dementia are more likely to be sexually active than not. The most common change is a lack or loss or sexual desire. Inappropriate sexual behaviors occur in a minority of patients (28%) and can be usually managed with behavioral measures, with the use of pharmacotherapy for symptomatic management in refractory cases.

Other clinical and ethical concerns in dementia include the capacity to consent to sexual intimacy, the formation of new relationships, sexuality in long-term residential facilities, and vulnerability to sexual abuse. Dementia care guidelines recommend a low threshold of suspicion for abuse, with a focus on patient safety. These must, however, be counterweighed by respect for patient autonomy and wishes.

Keywords
Sexuality, sexual health, ageing sexuality, physical intimacy, dementia, cognitive decline, inappropriate sexual behaviors

Introduction

Dementia has been defined as an acquired syndrome of intellectual impairment produced by brain dysfunction, usually organic. Further, one of the earliest operationalized definitions of dementia requires the presence of an acquired and persistent impairment of intellectual function with compromise in at least 3 of the following spheres of mental activity-language, memory, visuospatial skills, emotion or personality, and cognition. Neurocognitive disorders, the recently proposed alternative to the construct of dementia has been similarly defined as a group of disorders where the primary clinical deficit lies within cognitive function and which are acquired disorders, rather than developmental.

Sexuality has been defined as one of the central aspects of being human throughout life, which encompasses various constructs, including sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. The definition goes on to explain that sexuality is both experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles, and relationships. Further, while sexuality can include all of these dimensions, not all of them may be always experienced or expressed. Finally, sexuality is influenced by the interaction of various biological, psychological, social, economic, political, cultural, legal, historical, religious, and spiritual factors.
Dementia is associated with a progressive, often irreversible loss of the ability to function independently in several domains of life—biological, social, and occupational. This is expected to eventually affect sexuality and other forms of intimacy between the person living with dementia and the partner.\textsuperscript{5,6}

However, the diagnosis of a dementia or major neurocognitive disorder does not imply the cessation of sexuality in the older adult. The sexuality and sexual health of the person with dementia and his or her partner (if in a relationship) are vital components of the health and well-being of older adults.\textsuperscript{7,8}

For several personal, professional, ethical and sociocultural reasons, discussion of the sexual health of the person with dementia and his or her partner may not usually find their way into discussion within the health care network. Some of these reasons are age related and may include (a) a discomfort in discussing sexuality in older adults, (b) the fear of causing social or cultural offense, and (c) the assumption that the cessation of the reproductive period implies the end of sexual life in older adults. In older adults with dementia, there is also, often, a tendency to focus on the preservation of cognition and independence, with relative neglect of the need for physical and emotional intimacy or the quality of life of the individual.\textsuperscript{9,10}

Aging research on sexuality in dementia tends to be sparse. Where available, the focus of research is often upon the prevention and management of inappropriate sexual behavior.\textsuperscript{11} However, most common concern reported in a person with dementia by the partner is apathy and a loss of interest in sexual activity.\textsuperscript{5,12}

An important issue with regard to sexuality in dementia is that of capacity and competence. The capacity of a person with dementia to consent to sexual intimacy is central to all discussions of sexuality.\textsuperscript{13} Patients, partners, clinicians, and caregivers often conflate the diagnosis of dementia with the loss of consent and assume that dementia makes a person ineligible to participate in sexual activity, by default. Persons with dementia may retain capacity until moderate stages of disease severity.\textsuperscript{6}

The vulnerability to abuse because of impaired decision-making ability is an important consideration that may require inputs from health care providers.\textsuperscript{14} Other related concerns are (a) the impact of institutionalization, including placement in a nursing home on sexuality and (b) the formation of new relationships after the diagnosis of dementia. We review some of these issues further.\textsuperscript{15,16}

### Intimacy and Dementia in an Existing Relationship

Sexuality in persons living with dementia can be best understood within the context of a relationship (existing or sought). It lies within the continuum of need for intimacy by the older adult.\textsuperscript{6}

Intimacy or the state of being intimate can be defined as a warm relationship developing, often over long association, with a sense of belonging to and disclosure of one’s deepest nature to another.\textsuperscript{17}

Moss and Schwebel have proposed a definition for romantic intimacy in 1993, which consists of 5 components:

1. Commitment—the desire to remain with a partner permanently.
2. Affect intimacy—the emotional depth and closeness shared by a couple.
3. Cognitive intimacy—the shared thinking, information, values, and goals within the relationship.
4. Physical intimacy—the shared physical attractiveness, encounters, proximity, and sexuality within the relationship.
5. Mutuality—the mutual interaction and exchange, though partners may often invest differing levels of energy into the maintenance of intimacy.

This definition is not without its limitations and tends to conceptualize intimacy within a monogamous preexisting relationship. However, it is a useful framework to understand the needs of a person living with dementia.\textsuperscript{18}

The diagnosis of dementia can affect an individual’s preexisting relationships in significant ways, most commonly with their partner or spouse. Within a marriage, the patient and their spouse often need to adapt to changing roles. They may need to prepare for and adapt to the loss of role of the person with dementia and his or her increasing dependence.\textsuperscript{7,8} There is a further need for role flexibility and role reversal, with the blurring of traditional gender-based roles, particularly in a developing country such as India.\textsuperscript{19} Spouses and partners will often also need to master new skills such as the management of finances and household skills.\textsuperscript{20}

The role strain in the relationship, along with the impending sense of mortality and loss of selfhood can undoubtedly put strain upon an intimate relationship.\textsuperscript{12} The dementia by itself may not be the only cause of strain, with concerns including the management of other illnesses, loss of employment, financial constraints, loneliness, and social isolation being pertinent to the aging couple.\textsuperscript{6,12}

The most important predictor of the quality of the relationship post the onset of dementia, however, is the quality of the relationship before the onset of dementia.\textsuperscript{12} Despite the multiplicity of stressors placed upon the relationship, not all changes in the relationship may be necessarily negative. The resilience of the person with dementia and the partner as well as the presence of a strong and reliable social support system are positive prognostic factors for intimacy.\textsuperscript{5,12}

Phyllis Braudy Harris, in a qualitative study of intimacy and sexuality in early stage dementia published in 2009, interviewed 16 persons with dementia and 16 caregivers. Of these, 12 participants (patients and caregivers) reported an overall increase in the quality of intimacy in the relationship, despite a decline in sexual intimacy. The positive changes...
Sexual Activity in Dementia

Patients with dementia often continue to be sexually active, though changes in the way in which they express and act out upon their sexuality may occur with a decline in cognition. The National Social Life, Health and Aging Project (NSHAP) examined aging, sexual functioning, and the relationship of both factors with the cognitive functioning of older adults aged 62 to 91 years dwelling in their homes in the community, in North America.21 The study had a response rate of 74%, unusually high among studies examining sexuality. Among the respondents, 46% of all men and 18% of all women living with dementia self-reported as sexually active. Further, of older persons living with dementia who were in a relationship, 59% of men and 51% of women self-reported as sexually active. Amongst the oldest respondents, aged 80 to 91 years, over 40% of men and women self-reported as sexually active. Strikingly, 77% of all respondents reported to 91 years, over 40% of men and women self-reported as sexually active. Amongst the oldest respondents, aged 80 years, 59% of men and 51% of women self-reported as sexually active. Further, of older persons living with dementia who were in a relationship, 59% of men and 51% of women self-reported as sexually active. Amongst the oldest respondents, aged 80 to 91 years, over 40% of men and women self-reported as sexually active. Strikingly, 77% of all respondents reported to 91 years, over 40% of men and women self-reported as sexually active. Amongst the oldest respondents, aged 80 to 91 years, over 40% of men and women self-reported as sexually active. 

The study appears likely to have sampled patients with mild cognitive impairment and mild-to-moderate dementia because of the setting and nature of recruitment. It appeared to indicate older adults with dementia continued to be sexually active in the initial stages of the disease, at least. It further implied that dementia was not associated with a significant rise in sexual dysfunction in older adults, in the face of preserved ability to function and live independently in the community.21 However, despite relatively intact sexuality, persons with dementia were not free of problems unique to the degenerative process and loss of autonomy, with some indication of a vulnerability to abuse and coercion.21

The English Longitudinal Study on Aging (LSA), on the other hand, looked at the relationship between sexual activity and cognitive functioning in community dwelling older adults aged 50 to 90 years of age.22 The response rate here was lower, at around 67%. Of the respondents, men and women who were sexually active were found to have better cognitive functioning, greater levels of physical activity and an overall better quality of life. Respondents who were sexually active were also more likely to be younger, had a number of years of formal education and higher levels of personal wealth than respondents who were not sexually active.22 This could be interpreted as sexual functioning being a marker of better functioning in the older adult, or as a putative protective factor (as suggested by the authors) against cognitive decline.

Other aging studies have reported higher rates of sexual dysfunction as well as a change in sexual behaviors in persons with mild cognitive impairment (MCI) and dementia when compared to those without cognitive impairment.24 However, strikingly, these appear to be independent of the degree of impairment, age, gender, number of years of education, number of years of illness, or medication.23-25

Changes in Sexuality in Dementia

The most frequent changes in sexual behavior reported are (a) a decrease in or loss of interest in sexual activity (or apathy), (b) awkwardly conducted or sequenced sexual activity, (c) requests for forms of sexual behaviors or intimacy that are outside the usual repertoire of the relationship, (d) participation in sexual activity in the absence of or decreased physiological arousal, and (e) a lack of consideration for the responses and satisfaction of the partner.6,12

The most common dysfunctions reported are erectile dysfunction (40%-55%) in men and decreased desire (60%) in women.26,27 Despite apathy being the commonest change in sexual behavior, the lack of loss of sexual desire does not appear to be of major concern to persons with dementia, perhaps because of the lack of distress.26,27
Specific types of dementia may be associated with sexual dysfunction. Over 50% of men with Alzheimer’s disease report erectile dysfunction, significantly higher than age-matched adults without dementia. A study by Zeiss et al, in 1990, reported erectile dysfunction in 53% of 55 men with Alzheimer’s disease, which appeared to be independent of age, severity of cognitive impairment, years of education, physical health, or medication. This appears to suggest that erectile dysfunction may be a primary problem because of the disease process itself and reflect vascular pathology and amyloid burden. A study by Yang, in 2015, has shown in a 7-year follow-up study of 4153 patients that with newly diagnosed erectile dysfunction (ED) patients were 1.68 times more likely to develop Alzheimer’s dementia than those without ED. However, ED appeared to also be associated with a higher risk of any dementia, perhaps reflecting vascular health.

Unlike men, there are no studies which have examined sexual dysfunction in women with dementia. In studies which have examined sexual dysfunction among both genders such as the NSHAP, decreased sexual desire is reported in around 60% of women with dementia. In both men and women with dementia, disorders of sexual arousal appear to be less prevalent than in cognitively normal older adults, probably representing loss of cortical inhibitory activity.

Non-Alzheimer’s dementias are associated with a higher prevalence of inappropriate sexual behaviors (28%) than Alzheimer’s dementias (7%-8%). There is often concern about the possibility of inappropriate sexual behaviors associated with fronto-temporal dementia. However, the most common change in behavior associated with fronto-temporal dementia is apathy and a loss of interest rather than increased interest in sex associated with left frontal lobe impairment. Vascular dementias, however, appear to be over-represented (55%) amongst persons with dementia having inappropriate sexual behaviour. Right frontal lobe impairment has been frequently associated with inappropriate behavior, independent of etiology. The frontal dysconnectivity syndrome seen in the non-Alzheimer’s dementias may indicate a common neurobiological basis to inappropriate behaviors.

### Consent in Dementia

The question of consent lies at the heart of the discussion regarding the ability of a person with dementia to participate in sexual activity. The diagnosis of dementia by itself, is not sufficient to conclude that the older adult will be unable to provide consent. Richardson has postulated 3 prerequisites to valid consent in a civil capacity, which may be extrapolated to sexuality in dementia:

1. The presence of intact capacity
2. The absence of coercion
3. The absence of an insane delusion

The capacity of an individual to make a decision, including in dementia, is a deeply contextual ability. It is specific to the time, person, and place of interaction. A person with dementia may thus retain capacity in the early stages of the illness, but may acquire impairment in capacity in the later stages. However, with the progression of dementia, some loss of judgment and decision-making ability can be expected, predisposing to incapacity over time. Dementias in which a fluctuation in the clinical course is expected, such as dementia in Lewy Body Disease (DLBD) and vascular dementias, may similarly be associated with capacity on some occasions and incapacity on other occasions.

When required to assess the capacity of the individual to participate in sexual activity, the health care provider and the partner are recommended to consider the subdomains of information, comprehension, reasoning, and communication which constitute capacity. In situations where the person with dementia appears to understand the nature of the sexual activity, express interest or desire in the act, and indicate active assent, consent may be considered valid.

The presence of an unequal relationship, as between a patient and a health care provider, or financial and physical dependence are reasons for concern. They may be indicative of the possibility of coercion and require evaluation.

Similarly, the presence of behavioral and psychological symptoms of dementia (BPSD), while not a contraindication to sexual activity, may indicate the presence of what Richardson considered an insane delusion. Further, the presence of BPSD, in and of itself, is a reliable marker of the severity of impairment and a poor prognostic factor, and may thus be associated with a greater risk for incapacity.

Thus, in cases of doubtful consent, dementia care guidelines often recommend that the partner let themselves be guided by the nature of the relationship and the sexual preferences of the person prior to the onset of dementia. New onset paraphilias, for example, may be indicative of impaired capacity. Consent is recommended to be assertive, and if the person with dementia appears to be an inactive participant during physical intimacy, it is best halted. Similarly, the consent of the partner is just as important and can be considered so that the relationship does feel exploitative.

### Dementia and the Formation of a New Relationship

The formation of new relationships in persons with dementia is often of greater concern than a preexisting relationship because it raises the question of consent, as discussed above.

Lichtenberg and Strzepek laid out guidelines which may be used to help health care providers in assessing the capacity of an institutionalized patient with dementia to participate in sexual activity. Capacity to consent to and participate in sexual activity is based on the following considerations:

1. The patient’s awareness about the relationship
   a. Is the patient aware of the person who is initiating sexual contact?
b. Does the patient believe that the person initiating sexual contact is a spouse and thus acquiesce out of a delusion, or are they cognizant of the other person’s identity and intent?
c. Can the patient state the level of sexual intimacy that they would be comfortable with?

2. The patient’s ability to avoid any exploitation
   a. Is the behavior consistent with the patient’s formerly held beliefs/values?
   b. Does the patient have the capacity to communicate refusal of any uninvited sexual contact?

3. The patient’s awareness of potential risks
   a. Does a patient realize that this relationship may be time-limited (that the placement in the care unit may be temporary)?
   b. Is the patient able to describe how they will react if or when the relationship ends?

**Definition and Classification of Inappropriate Sexual Behavior (ISB) in Persons With Dementia**

Sexual behaviors in dementia can be categorized as (a) appropriate, (b) ambiguous or (#) inappropriate in nature.6,11

Kate de Medeiros defined inappropriate sexual behavior (ISB) in dementia as a specific sexual behavior which is marked by an apparent loss of control or by intimacy-seeking misplaced in the social context or which is directed toward the wrong target; this behavior may be not sexual in its form but may be so in its suggestion.33

ISB in dementia may be overt or implied and can be classified as6:

1. Inappropriate sexual talk—including using sexually explicit language which is out of keeping with the premorbid personality of the patient
2. Sexual acting out—including clearly sexual acts that occur in an inappropriate context, in isolation or involving other people
3. Implied sexual acts—including viewing pornographic material in an inappropriate context or requesting for genital care that is unnecessary
4. False sexual allegations—may occur as part of BPSD, but the possibility of sexual abuse must always be considered

An alternate classificatory systems for ISB is division into conventional and unconventional sexual behaviours.6 However, this has been criticized for its value-laden differentiation based on social mores and cultural values.

ISB have been reported to occur in between 7% and 25% of patients with dementia, and are strongly correlated with the presence of other BPSD.6,11,33 Of the types of ISB, inappropriate sexual talk (60% of all ISB) appears to be the most common presentation.11,33 Physical ISB, when it does occur, appears to occur more commonly in men than women, and may represent premorbid gender-based roles.6

**Assessment of ISB**

The assessment of ISBs, which are often highly distressing to the caregivers, are recommended to be conducted gently and in a nonjudgmental manner, with evaluation of the context of the behavior and possible maintaining factors in the environment.

There are several rating scales such as available which can be used to record and monitor the severity of ISBs. Scales such as the Ryden Aggression Scale (RAS), the Overt Behavior Scale (OAB), the Overt Aggression Scale (OAS), and the Cohen-Mansfield Agitation Inventory (CMAI) assess several categories of problem behaviors in dementia, which include ISBs.6 The OBS specifies 6 ISBs, which can be scored upon the basis of frequency and severity into 4 levels as follows34:

- Level 1. Sexual talk and touching (genital)
- Level 2. Exhibitionism and masturbation
- Level 3. Touching (genital)
- Level 4. Sexual assault or rape

The St. Andrews Sexual Behavior Assessment (SASBA), is standardized rating scale, which was developed and validated along the lines of the OBS in order to assess ISB, over a continuous prospective period of observation in formal care environments, such as nursing homes.35 It is based upon objective observation and is intended to be filled out by the formal caregiver in the residential care setting, after suitable training. The SASBA assesses 4 categories of ISBs—

1. Verbal comments
2. Noncontact behavior
3. Exposure of one’s self
4. Touching other persons inappropriately

Caregivers are asked to rate the severity of each category of the ISB on a scale from 1 to 4 in the SASBA.35 The scale also noted the antecedents to the ISBs as well as the interventions used to manage them. A key point is that the SASBA allows for the serial monitoring of the severity of ISBs in dementia and can be used to assess the response to a management plan for the ISBs.35

**Management of ISBs**

*Nonpharmacological Management*

Nonpharmacological management of ISBs are usually the first line of management and include6,11,36,37:
1. Environmental modification: An evaluation and remediation of maintaining factors in the environment such as under-stimulation or uncomfortable clothing as well as optimum temperature control often go a long way toward controlling ISB. It is also recommended that contact with the family member, health care provider or patient toward whom the ISB is directed be avoided, far as is possible. If the ISB is directed toward the primary caregiver, from whom prolonged separation may not be possible, it is recommended that they, at the very least, leave the room until the patient stops acting out.

1. Behavioral management: The intent behind a significant proportion of ISB appears to be to seek physical intimacy, and thus, providing the patient with alternatives such as soft toys to cuddle or aids for private masturbation may be attempted, with due regard for patient safety. A change in clothing to material than buttons or zips up at the back and cannot be shed easily may also be attempted. Refusal to the patient on perceived approach is recommended to be prompt and gently but firmly worded, with attempts to distract them or guide them away from the source of stimulation.

Pharmacological Management

Pharmacological management of ISB are usually be attempted only when nonpharmacological measures fail. There is only anecdotal evidence from case reports and case series available, much of which is extrapolated from evidence of the management of BPSD in dementia.11,36,37

1. Antidepressants: Case reports document the use of antidepressants based upon evidence derived from their propensity to cause sexual dysfunction. Antidepressant with sedative properties such as paroxetine, citalopram, mirtazapine and trazodone appear to fair better, probably because of their ability to bring down the level of cognitive arousal.

2. Antipsychotics: Antipsychotics such as haloperidol, risperidone and quetiapine have anecdotal evidence in reduction of acting out, probably by neuroleptization and associated hyperprolactinemia.

3. Anticonvulsants: Anticonvulsants such as benzodiazepines, carbamazepine, valproate, gabapentin, pregablin and topiramate also have anecdotal evidence derived from their cortical inhibitory action, but the risk of paradoxical activation must be borne in mind.

4. Treatment for dementia: Cholinesterase inhibitors such as donepezil and the glutamatergic antagonist memantine, have evidence in the management of other BPSD and may benefit some patients with ISB.

5. Drugs with antiandrogen action: Drugs with antiandrogenic activity such as medroxy-progesterone acetate, ethinyl-estradiol, finasteride, ketoconazole, cimetidine and spironolactone act by reducing serum testosterone levels and bring down ISB. However, the ethics of using chemical castration in patients with dementia is questionable. They are also associated with considerable morbidity including the risk of osteoporosis and falls. These agents must be used only as a last resort, in case of persistent risk of harm to self or others.

Sexuality and Residential Care

The sexuality of older adults in long term residential care facilities such as old age homes, nursing homes, centers for healthy aging, dementia care centers and palliative care centers is an important, though often overlooked area of in the HCN.12 A HelpAge India report in 2014 indicated that older adults stay with their family in the community.13 Despite this, aging of India’s population also means that there is a corresponding rise in the need for long term residential care facilities for the elderly.

Systematic studies on conditions in and needs of older adults in old age homes are relatively lacking. In the USA, as of 2001, 5% of adults over 65 years of age and 20% of adults over 85 years of age lived in nursing homes. Further, an adult over the age of 65 years in the USA has a 25% chance of residing in an old age home before death.13 India may expect a comparable proportion of older adults in long term residential facilities (LTRF). Of these, between 50% and 67% of residents are expected to have dementia.13

Institutionalization in LTRF often requires the older adult, irrespective of their functional capacity to submit to the regime and routine established by the administration.19 This includes relinquishing autonomy and privacy, and impinges upon their sexuality. LTRF and the families of inmates may take an adversarial role and act as a barrier to their needs for physical intimacy.20

The older adult’s need for physical intimacy is more often nonsexual than otherwise, and often a means of seeking reassurance and comfort. These needs may span the gamut from simple hand holding to the need for conjugal visits from their partner. Potential complications ensue when decision making capacity is impaired, or both partners in a relationship are inmates of the LTRF, or an inmate enters into a new relationship within the LTRF, or the inmate expressed their sexuality in an inappropriate or nonconsensual manner with another inmate or staff.26,27

It is recommended that care homes formulate policies to explicitly address the needs for physical intimacy, including sexual expression of the older adult in the LTRF.27,15 A collaborative approach with the inmate and partner, with involvement of the family and physician when appropriate often yields a better outcome than a blanket censorship of all intimacy.15 The capacity of the inmate can be factored into the management plan and their needs and dignity respected.
It is also recommended that LTRF respect the privacy of their inmates, including possibility of conjugal visits and adopt a knock before entering policy. This must be counterweighed against due caution regarding the risk for exploitation and abuse of patients with impaired decision making capacity.5,13

This a balance that the LTRF can tread in order to respect the rights of its inmates and staff with the need to ensure their safety and well-being. There are educational resources available such as a training video on “Freedom of Sexual Expression: Dementia and Resident Rights in Long-Term Care Facilities” by the Hebrew Home in New York. Resource material and studies in the Indian context are however lacking, and would be of considerable importance in shaping policies.13,15

**Sexual Abuse in Dementia**

Elder abuse was defined by the WHO in 2002 as “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.”46

Sexual violence was further defined by the WHO in 2011 as “any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic or otherwise directed against a person’s sexuality using coercion, by any person regardless of their relationship to the victim, in any setting, including but not limited to home and work.”41

Mild cognitive impairment and dementia are risk factors for sexual abuse. Social care networks and health care providers may also be less likely to take reporting seriously in patient with impaired cognitive capacity.

Burgess and Phillips, in 2006, examined 284 cases of older adults who reported sexual abuse from the USA, in a retrospective analysis, using the comprehensive sexual assault assessment (CSAAT). Persons with dementia constituted 60% of the sample.14 Persons with dementia were more likely to be abused sexually than older adults without dementia. Further, they were more likely to be abused by someone known to them (family member, formal caregiver or another member of the nursing home) rather than a stranger. Persons with dementia were found to be more likely to have faced violence and indicate abuse through nonverbal communication than persons without dementia. They were also more likely to have impaired capacity and have faced coercion than those without dementia. The abusers of older adults with dementia were also less likely to escape conviction because of these reasons.14

Screening instruments such as the Elder Abuse Suspicion Index (EASI) may be used to assess sexual abuse at the primary care level.40 Sexual abuse in dementia can be managed as in other elder abuse, by a multi-disciplinary team (MDT), with a focus on safety and appropriate legal assistance, as appropriate. India does not yet have provisions for the mandatory reporting of sexual abuse in older adults or adult protection services (APS), measures which may be protective.42

**Conclusion**

Sexuality and sexual health are fundamental rights of older adults, even in the presence of dementia. The diagnosis of dementia does imply the cessation of sexual life or the loss of capacity to consent to sexual intimacy. Older adults with dementia often continue to be sexually active and retain capacity to consent until moderate stages of dementia.

The most common change in dementia is a lack or loss of sexual desire. Inappropriate sexual behavior does occurs in a minority of patients and requires training in sensitivity during evaluation and management. Other important concerns are sexuality in residential care, and vulnerability to sexual abuse, which can be approached with due sensitivity, counterbalanced by a respect for patient autonomy.43

**Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The authors received no financial support for the research, authorship, and/or publication of this article.

**ORCID iD**

Migita D’cruz https://orcid.org/0000-0002-7568-6436

**References**

1. Cummings JL, Benson DF, Benson DF. Dementia: A clinical approach. Butterworth-Heinemann. 1992: 576 p. https://trove.nla.gov.au/work/7343631/version/8449487.
2. World Health Organization. The ICD-10 classification of mental and behavioral disorders: clinical descriptions and diagnostic guidelines. Geneva. 1992. http://www.who.int/classifications/icd/en/bluebook.pdf.**
3. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. 2013. https://www.psychiatry.org/psychiatrists/practice/dsm.**
4. WHO. Defining sexual health. WHO. World Health Organization. http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/. 2017.
5. Steffens DC, Blazer DG, Thakur ME. The American Psychiatric Publishing Textbook of Geriatric Psychiatry. 5th ed. American Psychiatric Publishing; 2015. http://psychiatryonline.org/doi/book/10.1176/appi.books.9781615370054.
6. Oxford Textbook of Old Age Psychiatry [Internet]. Oxford Textbook of Old Age Psychiatry. Oxford University Press; 2013. https://oxfordmedicine.com/view/10.1093/med/9780199644957.001.0001/med-9780199644957.
7. Wornell DP. Sexuality and Dementia. Today's Geriatric Medicine. 2014, Vol. 7 No. 2 P. 9. Kaplan HS. Sex, intimacy, and the aging process. J American Acad Psychoanal. June 1, 1990;18(2):185-205. https://guilfordjournals.com/doi/pdf/10.1521/jaap.1.1990.18.2.185.

8. Sexuality and Dementia. Family Caregiver Alliance. https://www.caregiver.org/sexuality-and-dementia. **

9. Rao TS. Forbidden fruit in the golden years: elderly sexuality. J Geriatr Ment Health. 2014;1:8-13. http://www.jgmh.org/text.asp?2014/1/8/141917.

10. Wilkins JM. More Than capacity: alternatives for sexual activity-and-cogniti-2.

11. De Giorgi R, Series H. Treatment of inappropriate sexual behavior in dementia. Curr Treat Options Neurol. 2016;18. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4980403/.

12. Harris PB. Intimacy, sexuality, and early-stage dementia. 2009;15. https://collected.jcu.edu/soc-facpub/2/**

13. Wilkins JM. More Than capacity: alternatives for sexual decision making for individuals with dementia. Gerontologist. October 1, 2015;55(5):716-723. https://academic.oup.com/gerontologist/article/55/5/716/2605290.

14. Burgess AW, Phillips SL Sexual abuse, trauma and dementia. J Geriatr Psychiatry. 2014;53:300-306. https://journals.sagepub.com/doi/abs/10.1191/0269216304pm941oa.

15. Wiskerke E, Manthorpe J. Intimacy between care home residents with dementia: Findings from a review of the literature: Dementia. July 13, 2016. **https://journals.sagepub. com/doi/10.1177/1471301216659771.

16. Lemiex L., Kaiser S., Pereira J., Meadows L.M. Sexuality in palliative care: patient perspectives. Palliat Med. October 2004;18(7):630-637. https://journals.sagepub.com/doi/10.1191/0269216304pm941oa.

17. Collins WA, Sroufe LA. Capacity for intimate relationships: a developmental construction. Reprinted from: the developmental construction. Reprinted from: the development of romantic relationships in adolescence; 1999; pp. 125-147. Cambridge University Press. http://www.psychology.sunysb.edu/attachment/online/capacity_for_intimate.pdf.

18. Moss BF, Schwebel AI. Defining intimacy in romantic relationships. Family relations: an interdisciplinary JAppl Family Studies. 1993;42(1):31-37. https://doi.org/10.2307/584918.

19. Krala G, Subramanyam A, Pinto C. Sexuality: desire, activity and intimacy in the elderly. Indian J Psychiatry. 2011;53:300-306. http://www.indianjpsychiatry.org/text.asp?2011/53/4/300/91902.

20. Dhingra I, De Sousa A, Sonavane S. Sexuality in older adults: clinical and psychosocial dilemmas. J Geriatr Ment Health. 2016;3:131-139. http://www.jgmh.org/text.asp?2016/3/2/131/195629.

21. Lindau ST, Dale W, Feldmeth G, et al. Sexuality and cognitive status: a USA. Nationally representative study of home-dwelling older adults. J Am Geriatr Soc. 2018;66(10):1902-1910. https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.15511.

22. Wright H, Jenks RA. Sex on the brain! associations between sexual activity and cognitive function in older age. Age Ageing. March 2016;45(2):313-317. https://pureportal.coventry.ac.uk/en/publications/sex-on-the-brain-associations-between-sexual-activity-and-cogniti-2.

23. Koledzijaczek K, Drewelies J, Deeg DJH, Huisman M, Gerstorf D. Perceived importance and enjoyment of sexuality in late midlife: cohort differences in the longitudinal aging study amsterdam (LASA). Sex Res Soc Policy. September 11, 2020.**volume https://doi.org/10.1007/s11195-020-00486-2.

24. Tsatali M, Tsolaki M. Sexual function in normal elders, MCI and patients with mild dementia. Sex Disabil. June 1, 2014;32(2):205-219. https://link.springer.com/article/10.1007%2Fs1195-014-9353-9.

25. Rector S, Stiritz S, Morley JE. Sexuality, aging, and dementia. J Nutr Health Aging. April 1, 2020;24(4):366-370. https://link.springer.com/article/10.1007/s12603-020-1345-0.

26. Haddad PM, Benbow SM. Sexual problems associated with dementia: part 1. Problems and their consequences. Int J Geriatr Psychiatry. 1993;8(7):547-551. https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.930080703.

27. Haddad PM, Benbow SM. Sexual problems associated with dementia: part 2. Aetiology, assessment and treatment. Int J Geriatr Psychiatry. 1993;8(8):631-637. https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.930080803.

28. Zeiss AM, Davies HD, Wood M, Tinklenberg JR. The incidence and correlates of erectile problems in patients with Alzheimer’s disease. Arch Sex Behav. August 1990;19(4):325-331. https://link.springer.com/article/10.1007%2FBF01541927.

29. Yang C-M, Shen Y-C, Weng S-F, Wang J-J, Tien K-J. Increased risk of dementia in patients with erectile dysfunction. Medicine (Baltimore). June 19, 2015;94(24). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4616558/.

30. Palmer BW, Harmell AL. Assessment of health care decision-making capacity. Arch Clin Neuropsychol. September 2016;31(6):530-540. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5007079/.

31. Rosner R, Scott C, Scott C. Principles and Practice of Forensic Psychiatry. CRC Press; 2017. https://www.taylorfrancis.com/books/e/9781315381480.

32. Lichtenberg PA. Sexuality and physical intimacy in long term care. Occup Ther Health Care. January 2014;28(1):42-50. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4550102/.

33. de Medeiros K, Rosenborg PB, Baker AS, Onyike CU. Improper sexual behaviors in elders with dementia living in residential care. Dement Geriatr Cogn Disord. 2008;26(4):370-377. https://www.karger.com/Article/Abstract/163219.

34. Kelly G, Todd J, Simpson G, Kremer P, Martin C. The overt behavior scale (OBS): a tool for measuring challenging behaviors following ABI in community settings. Brain Injury.
35. Knight C, Alderman N, Johnson C, Green S, Birkett-Swan L, Yorstan G. The St Andrew’s Sexual Behavior Assessment (SASBA): development of a standardized recording instrument for the measurement and assessment of challenging sexual behavior in people with progressive and acquired neurological impairment. *Neuropsychol Rehabil*. April 2008;18(2):129-159. https://pubmed.ncbi.nlm.nih.gov/18350412/.

36. Alagiakrishnan K, Lim D, Brahim A, et al. Sexually inappropriate behavior in demented elderly people. *Postgrad Med J*. July 1, 2005;81(957):463-466. https://pmj.bmj.com/content/81/957/463.

37. Joller P, Gupta N, Seitz DP, Frank C, Gibson M, Gill SS. Approach to inappropriate sexual behavior in people with dementia. *Can Fam Physician*. March 2013;59(3):255-260. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3596201/.

38. HelpAge India. Report on Elder Abuse in India. HelpAge India. https://www.helpageindia.org/pdf/highlight-archives.pdf. 2014.

39. de Medeiros MMD, Carletti TM, Magno MB, Maia LC, Cavalcanti YW, Rodrigues-Garcia RCM. Does the institutionalization influence elderly’s quality of life? A systematic review and meta-analysis. *BMC Geriatrics*. February 5, 2020;20(1):44. https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-1452-0.

40. World Health Organization, Université de Genève, eds. A global response to elder abuse and neglect: building primary health care capacity to deal with the problem worldwide: main report. World Health Organization; 2008. 134 p. https://www.who.int/ageing/publications/ELDER_DocAugust08.pdf?ua=1.

41. World Health Organization. Sexual Violence. World Report on Violence and Health. Geneva, Switzerland: World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/42495/9241545615_eng.pdf?sequence=1. 2002.

42. HelpAge India. Elder Abuse in India. Country Report for the World Health Organization. https://www.who.int/ageing/projects/elder_abuse/alc_ea_ind.pdf?ua=1. 2018.

43. Rao TS, Gopalakrishnan R, Kuruvilla A, Jacob KS. Social determinants of sexual health. *Indian J Psychiatry*. January 4, 2012;54(2):105. http://www.indianjpsychiatry.org/text.asp?2012/54/2/105/99527.