Influence of Cognitive Decline on Sexuality

in Individuals with Dementia and Their Caregivers

ABSTRACT

Sexuality is an important element of human life that is strongly influenced by the social environment. People assess themselves and relate their roles to one another in terms of sexuality. More attention must be directed at the sexual needs of individuals with dementia and their caregivers. A myth believed by society is that individuals with dementia are asexual and that sexual desires and needs for connection will wane over time; whereas in reality many couples living with dementia remain sexually active as the disease progresses. The sexual needs of individuals with dementia are similar to those of younger people but might vary in occurrence and expression. An increase or decline in sexual desire is dependent on the level of cognitive impairment. Sexuality in individuals with dementia may be expressed as inappropriate or hypersexual behavior due to disinhibition and forgetting social cues. Although hypersexuality is often less common than other challenging behaviors that can occur in dementia, it affects both the health of the individual with dementia and the health of his or her caregiver. [*Journal of Gerontological Nursing, 39*(11), 30-36.]

Dementia is a progressive condition that affects the brain and consequently impacts memory and alters behavior and one's personality (Higgins, Barker, & Begley, 2004). The end result of these changes is the individual with dementia becomes increasingly dependent on others for his or her daily functioning (American Psychiatric Association [APA], 2000). Attention in the literature related to Alzheimer's disease is most often focused on the slow, progressive nature of the cognitive decline as well as changes in behavior seen as the disease progresses. According to Black, Muralee, and Tampi (2005), Alzheimer's disease is the most common type of dementia, followed by Lewy body dementia and vascular dementia.

Sexuality is of great interest in today's society, but older adults with cognitive decline are not well represented in research studies. Sex is perceived to be for younger, attractive individuals. Sexual behavior between life partners when one has dementia is rarely addressed because of social discomfort with this behavior (Shaw, 2001). Thus, knowledge and attitudes about sexuality and cognitive decline are limited. Consideration or discussion about sexual behavior in individuals with dementia is perceived as a taboo subject by health care providers, who often do not mention the topic or ask questions about sexual function, even during health care assessments (Harris & Wier, 1998). The topic of sexuality and dementia is identified as an uncomfortable subject related to cultural values, personal feelings, or a lack of knowledge (Haddad & Benbow, 1993). Beliefs

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such as that sex is not relevant to individuals with dementia or that these individuals are asexual are common myths that limit the opportunities for an individual with dementia to engage in sexual activities (Dourado, Finamore, Barroso, Santos, & Laks, 2010).

The purpose of this review is to examine the current status of knowledge about the influence of cognitive decline on sexuality in individuals with dementia. Sub-aims for the review include an exploration about satisfaction with sexual relationships in married couples living with dementia and hypersexuality or inappropriate sexual behavior.

METHOD

The literature was searched for English-language articles focusing on sexuality in individuals with dementia. The EBSCO Host database was used in the search for peer-reviewed, full-text articles from 1990 to 2013. Keywords included *sexuality*, *dementia*, and *hypersexuality*. In addition to the search in the electronic database, relevant articles were identified through tracking references in meaningful articles and through a manual Internet literature search. Publications were screened by the authors to meet the following inclusion criteria: (a) community-dwelling individuals with dementia with a mean age of 65 or older; and (b) article title indicated a relationship between sex/sexuality and individuals experiencing cognitive decline or dementia.

Case reports and literature reviews were also included. In total, the search produced 86 references. Articles focusing mainly on physical disorders or medication were excluded. Additionally, articles were excluded when the individual with dementia resided in a nursing home. Only studies that provided relevant information on sexual behavior or information on sexuality in older individuals with dementia living in the community were included. Eight major articles (**Figure**) that met the inclusion criteria are summarized below. In contrast, the authors also conducted a search on two other behavioral problems associated with dementia. When key words *dementia* and *wandering* were used, 207 results were found, and similarly, *dementia and aggression* produced 561 results. This abundant number of references found on behavioral problems demonstrates the dearth of literature on sexual issues in dementia and is the reason why the authors included dated studies in addition to incorporating the latest research available. The lack of research in the area of sexuality in dementia can be attributed to its prevalence being underreported due to stigma, dif-

ficulty differentiating acceptable and unacceptable sexual behaviors, lack of a clear definition or common terminology for hypersexuality, and lack of research pertaining to older adults and sexuality as a whole. In addition, the majority of the studies conducted in this area involved individuals with dementia who resided in nursing facilities and those articles were not used in this analysis.

SEXUAL RELATIONSHIPS IN MARRIED INDIVIDUALS WITH DEMENTIA

Do married couples maintain a sexual relationship when one partner has dementia? Baikie (2002) reported declines in sexual activity in three fourths of individuals with dementia still living in the community. Caregivers identified problems regarding individuals with dementia who made frequent sexual advances but did not remember a previous episode of sexual intercourse that had just occurred earlier. Spousal caregivers were discouraged by sexual advances from a partner who no longer remembered their name or no longer recognized the caregiver spouse. In her research, Baikie (2002) also found that in women with dementia, there was both an increase and decrease in reported sex drive. In addition, some spousal caregivers viewed sexual activity as somewhat incestuous. Husband caregivers reported that their wives became scared when sexual activity was instigated and attributed this to their wives reverting back to childhood as a result of the disease process of dementia (Baikie, 2002).

On the other hand, the sexual relationship can also be viewed as a strength in spousal caregiving. The more the spouse can find sexual practices to be a source of support, reassurance, and a means of coping with progressive decline, the more likely the relationship will continue with high quality, including keeping the individual with dementia in the home setting. In addition, the ability to remain sexually active gives the individual with dementia a way in which to still provide something back to his or her partner. The benefits of remaining sexually active are multifaceted and important to the individual with dementia and his or her caregiving spouse. Another consideration regarding sexuality must be a concern for emotional disorders. Sexuality for both the individual with dementia and the caregiver can be affected by emotional disorders, such as depression, which may cause a lack of desire, but sexuality can also be a source of physical and emotional release that helps reduce depression (Davies, Zeiss, Shea, & Tinklenberg, 1998).

Two studies investigated sexual satisfaction among individuals with dementia and spouses (Ballard et al., 1997; Dourado et al., 2010). Ballard et al. (1997) investigated the percentage of couples, in which one person had a diagnosis of dementia, who continued to have a sexual relationship. The caregiver's level of satisfaction with the sexual relationship and the associations found with remaining sexually active were studied. Questions were asked of the caregiver while the individual with dementia was not in the room. The sample consisted of 40 (mean age = 78) married individuals with dementia with mild to moderate dementia and their caregiver spouses. Only 22.5% of couples continued to have a sexual relationship and all (100% of the couples who had sex) were satisfied with their sexuality and reported that their spouse with dementia was also satisfied. The majority of individuals with dementia not involved in a sexual relationship were reported by the caregiver to be satisfied. However, a minority of caregivers not sexually active (38.7%) reported dissatisfaction with their lack of a sexual relationship. A trend was noted for male caregivers to experience a continued sexual relationship. An inverse relationship was found between visual hallucinations and remaining sexually active. Individuals with dementia with higher abstract thinking were significantly more likely to continue in a sexual relationship. Among caregivers who were not sexually active and were dissatisfied with the situation, dissatisfaction was associated with a partner who had vascular dementia and a trend occurred toward association with younger individuals with dementia who had a higher level of retained language functioning. All questions in this study were directed to the caregivers, who reported perceptions of themselves as well as their spouses.

More recently, Dourado et al. (2010) investigated the presence of sexual activity and satisfaction between individuals with dementia ($N = 36$) and their spouses. Individuals with dementia studied were diagnosed with Alzheimer's disease with mild ($N = 15$) or moderate ($N = 21$) severity. Perceptions of both the individual with dementia and spouse were included in interviews. The presence of sexual activity was reported by 64% of individuals with dementia (14 men, 9 women) and 56% of the spouses (10 men, 10 women). Individuals with dementia were interviewed about the reasons for interruption of sexual activity and tended to blame their spouse for the interruption and resultant sexual dissatisfaction. An explanation offered by the researchers was that individuals with dementia tended to overestimate their sexual abilities. Caregivers reported the impact of Alzheimer's disease on marriage resulted in decreased sexual intimacy and changed family roles. Their relationship became more nonsexual as the disease progressed. A significant association was found between sexual satisfaction of spouses and the severity of Alzheimer's disease. Spouses of individuals with dementia with a mild level of symptoms experienced more sexual dissatisfaction than the moderately symptomatic group. An explanation might be that the loss of sexual intimacy is a more recent loss for spouses of individuals with dementia who have a mild level of symptoms, whereas spouses of individuals with dementia in the moderate stage had slowly adjusted to their routine.

Dissatisfaction reported by spouses resulted from their partner with dementia not being able to pay attention to their needs and feelings. Both individuals with dementia and caregivers confirmed similar reasons for sexual dissatisfaction, including erectile dysfunction and a lack of sexual desire in women.

The question of whether affection and sexual intimacy differed or changed over time in couples with dementia compared to healthy older couples was studied by Wright (1998). Findings indicated couples living with dementia had differences in affection and sexual intimacy compared to couples experiencing healthy aging. Findings identified that couples with Alzheimer's disease experienced significant declines: Affection declined significantly and fewer couples with Alzheimer's disease were sexually active compared to healthy older couples (27% versus 82%). This study included kissing as a sexual activity; therefore, the estimates of continued activity may be inflated. An interesting finding occurred at Time 2 on affection. Affection was rated significantly lower by spouses who were subsequently widowed or later had to place the individual with dementia in a nursing home. One question identified for future research is whether this lack of affection and interaction between spouses contributed to the later death or institutionalization of the individual with dementia. At Time 3, it was surprising to see that affection increased dramatically after nursing home placement. Another surprising finding was that a higher percentage of those individuals with dementia who were sexually active at Time 2 had remained at home at Time 3 but the numbers were too small to accurately determine the meaning of this finding. Declines noted in sexual activity may not only be attributed to cognitive decline in the individuals with dementia but may also result from declines in physical health experienced by the caregiver. Sexual activity in Alzheimer's disease couples was significantly positively related to physical health and negatively related to depressed mood (Wright, 1998).

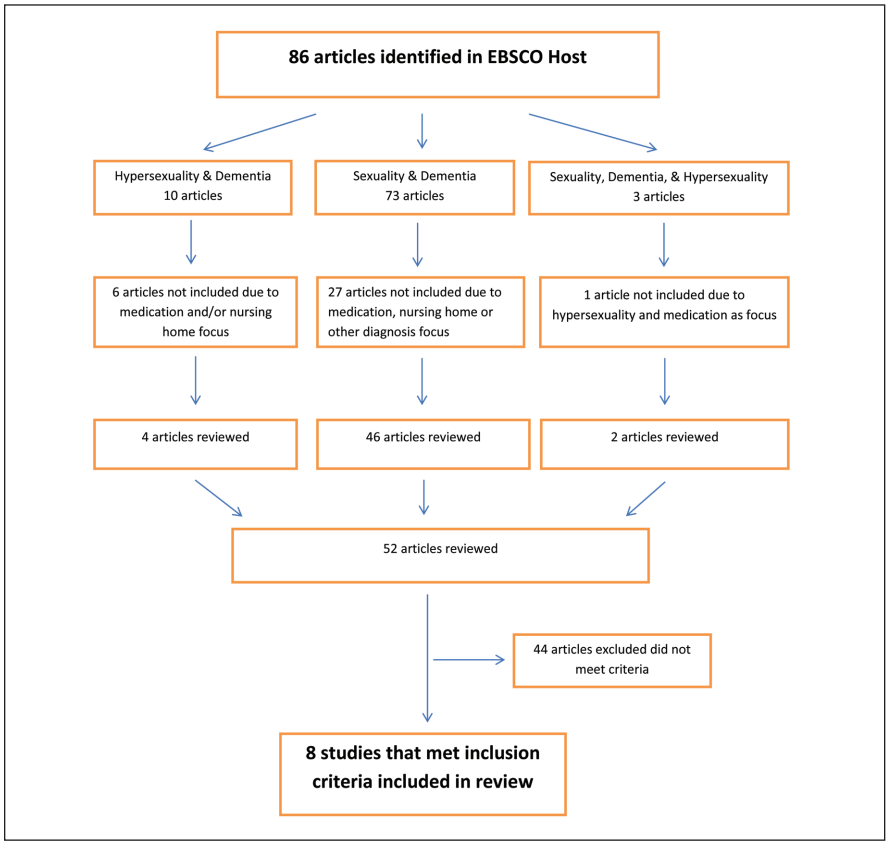

Figure. Literature review.

Overall, the quality of the sexual relationship ranks low in terms of reasons for placement in a nursing home. Davies, Sridhar, Newkirk, Beaudreau, and O'Hara (2012) found that diminished sexual relationship was ranked ninth among 13 factors involved in their consideration of placement in a nursing home setting, and was reported by 12 (22.2%) caregivers. The most common reasons for placement were patient functional status (55.6%), cognitive function (51.6%), or problems with incontinence (44.4%) (Davies et al., 2012).

HYPERSEXUALITY AND INAPPROPRIATE SEXUAL BEHAVIOR

Hypersexuality, also referred to in the literature as inappropriate sexual behavior (ISB) (Black et al., 2005), must be a consideration in the overall behavioral and psychological symptoms of dementia (Harris & Wier, 1998). Cognitive decline associated with dementia does not always diminish sexual urges (Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2011), and the need for sexual closeness does not cease with advanced age. In the first few stages of dementia, many people may become hypersexual whereas others express indifference toward sexuality (Tsatali et al., 2011).

Kuhn, Greiner, and Arseneau (1998) defined two types of behavior as hypersexuality: (a) persistent, uninhibited sexual behavior directed at oneself or others, and (b) inappropriate behavior in relation to others.

Wick and Zanni (2005) defined hypersexual behaviors to include compulsive masturbation in both public and private locations, fondling of breasts or other personal body parts of caregivers/other patients, flirtation, disrobing of self or others, and overt sexual acts. These acts are not

KEYPOINTS

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1. Additional research is needed to understand the sexual needs of individuals with dementia and their caregivers.
2. Health professionals need increased education about ways to assist individuals with dementia and their partners to cope with changes in intimacy and sexuality.
3. Opportunities must be created to enhance sexual relationships in couples with dementia.
4. Satisfying sexual relationships in couples with dementia may decrease caregiver burden, resulting in a delay of nursing home placement.

typically thought to be directed at a particular person but are considered random events that are not forms of sexual intimacy retained in Alzheimer's disease (Tsatali et al., 2011).

ISB occurs in approximately 7% to 25% of patients with dementia (Guay, 2008) and are more commonly observed in older men (Black et al., 2005). ISB is often underreported in comparison to other behavioral problems such as agitation, depression, and anxiety (Tsatali et al., 2011). Because sexual activity may increase in association with the progression of dementia, the result can be exhausting demands on sexual partners. Physical aggression may stem from this issue if the needs of the individual with dementia are not being met. These behaviors of individuals with dementia are some of the most challenging to curtail and present a challenge to health professionals in providing their care (Tsatali et al., 2011). Hypersexual behaviors also create problems for other residents, staff members, and families in nursing facilities (Black et al., 2005) in which they have to share their home following placement. Discussion occurred about including "hypersexual disorder" as a possible new disorder in the new *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (Kafka, 2010; Marshall & Briken, 2010; Reid, Garos, & Carpenter, 2011). This inclusion is a reflection of the increasing attention among clinicians and investigators of the possible impact hypersexual behaviors can have on the well-being and care environment of the individual with dementia (Mendez & Shapira, 2013) and the stress of his or her caregiver. The final decision made, however, was for non-inclusion in the newest edition.

According to Mendez and Shapira (2013), of all the dementias, behavioral variant frontotemporal dementia (bvFTD) may most often result in increased frequency of sexual activity. In their study, Mendez and Shapira (2013) compared 47 patients with bvFTD and 58 patients with early-onset Alzheimer's disease for the presence of hypersexual behavior. Six patients with bvFTD compared to no patients with Alzheimer's disease had three inclusion criteria for hypersexual behavior. These six patients with bvFTD had all four of the study characteristics for hypersexuality. Patients with both bvFTD and hypersexuality not only had sexual disinhibition but also increased sexual desire. These patients actively sought sexual stimulation and had a variety of sexual interests. Study findings indicated that hypersexual behaviors occurred in 6 (13%) patients with bvFTD in comparison to none of the patients with Alzheimer's disease.

Although hypersexuality is one of the more embarrassing problem behaviors for the caregiver that arises in dementia, it is also an atypical occurrence in the disease process (Robinson, 2003). According to Black et al. (2005), it can be hard for the caregiver to differentiate between hypersexuality and the normal needs of the individual with dementia for sex, physical closeness, and intimacy. Apathy is the most common form of ISB. Harris and Wier (1998) reviewed the research literature and found that the most frequent change in sexual behavior of individuals with dementia was increased sexual apathy. ISB frequently results in feelings of anxiety, embarrassment, or unease in the caregiver, making it more challenging for him or her to provide care in the home (Wallace & Safer, 2009). Care burden is amplified with these hypersexual behaviors (Bird & Moniz-Cook, 2008), which increase the likelihood of placement in a residential care facility (Alkhalil, Tanvir, Alkhalil, & Lowenthal, 2004).

DISCUSSION AND NURSING IMPLICATIONS

Sexuality and the need for sexual activity does not stop even with cognitive decline in dementia. As many as 20% to 30% of couples with a spouse with dementia report continued sexual activity. Although cognitive decline may alter the way sexual functioning is expressed, continuation of sexual activity as the disease progresses may be beneficial to keeping the individual with dementia at home and preventing nursing home admission (Davies et al., 1998; Wright, 1998). Many older couples with a spouse with dementia seem to desire intimacy despite progressive cognitive decline. These couples may be interested in interventions that address successful changes in sexuality caused by dementia. Health care professionals must be amenable to address the topic of sexuality when it arises. Simple

questions might be added to a routine assessment. The nurse at first assessment might use anticipatory guidance to inform the couple that changes in sexuality often accompany the declines experienced in dementia. One simple question to begin the conversation might be "How has dementia affected your sexual relationship?" Couples often show relief that the subject has been approached (Davies et al., 1998). Health declines in both the individual with dementia and caregiver must be investigated when decreased sexual activity is reported, as there may be a physiological cause for the sexual decline that is amenable to treatment.

According to Black et al. (2005), the first goal of the assessment should be to gather a comprehensive history, including a sexual history, which can be obtained from caregivers and family members when necessary. It is important to gather information directly from the individual with dementia whenever possible so that he or she is involved in the processing. In addition to gathering a complete history, a mental status examination and physical examination should also be performed.

A comprehensive assessment of sexual functioning includes evaluating the individual's interest in sex, any challenges with arousal, and problems reaching orgasm (Davies et al., 1998). When interviewing the individual with dementia, the interviewer should avoid asking questions regarding recall of specific information. Instead, questions should focus on the feelings the individual has toward sexuality and the role he or she hopes it continues to have in his or her life. In contrast, if the person being interviewed is the spouse without dementia, more detailed questions might be incorporated into the assessments following the development of rapport. A comfortable way to start asking the questions is to discuss the impact of dementia on sexuality and transitioning into questions pertaining to sexual thoughts and impulses (Davies et al., 1998).

In terms of assessments specific to ISB, there is an apparent lack of standardized assessment tools used for the neurologically impaired population (Johnson, Knight, & Alderman, 2006). Two basic behavior measurement tools, the Aggression Scale (Ryden, 1988) and Agitation Inventory (Cohen-Mansfield, Marx, & Rosenthal, 1989), include some categories relevant to ISB but do not focus entirely on this issue. A continuous assessment of the behaviors is the best approach to providing a more accurate representation of the frequency and nature of the ISB opposed to intermittent caregiver interviews (Johnson et al., 2006).

A number of online resources for support and information about FTD exist for both the patient and caregiver. The FTD Support Forum (http://www.ftdsupportforum.com) is an excellent tool because it is moderated and requires the user to register, which helps protect personal identification and makes the site more secure. The FTD Caregiver Support Center (http://www.ftdsupport.com) includes a checklist for caregivers and links to other resources, including other national caregiver sites as well as other helpful materials. The Association for Frontotemporal Degeneration (http://www.theaftd.org) provides a medical overview of FTD in addition to the latest clinical and treatment information as well as FTD in the news. Lastly, the FTD Support Group (http://www.ftdsg.org) includes a section on caregivers' stories and helpful tips to aid caregivers in coping with the progression of the disease process. In addition to these helpful online resources, it is important to remember the great resource in local Alzheimer's Association chapters. The Alzheimer's Association can assist the caregiver and care recipient in locating nearby support groups and other classes and events in addition to putting the family in contact with a licensed social worker. It is important that professionals know about these helpful resources for their clients, in addition to considering attending some of these educational classes.

This review had several limitations that should be noted. The few studies found exploring sexuality in individuals with dementia had small samples and were methodologically weak, thus the results are inconclusive. Most of the screening instruments for assessing cognitive function had few questions on sexual behavior. Very few studies were found that included the perspective of the individual with dementia. Most literature (with two exceptions [Dourado et al., 2010; Wright, 1998]) reported the spousal caregivers' perspectives of how the individual with dementia perceived the sexual situation. Future research must directly include the perspective of the individual with dementia.

Health professionals were uncomfortable exploring the area of sexual functioning, probably because individuals with dementia are viewed as asexual. Very few instruments were found that actually assessed sexual activity and dysfunction. As a result, health professionals did not assess for sexual dysfunction even in routine health assessments. To remedy the discomfort experienced by health professionals when assessing sexual dysfunction, curriculum and educational programs for all health professionals must include education on how to comfortably approach the topic of sexuality and complete an assessment of this area of function. Standardized patient simulation programs might include a case study about ISB in a couple with dementia. After the assessment or intervention is completed, the trained standardized patient would then provide feedback to the student about experienced levels of comfort with the assessment. Assessing and analyzing the occurrence of problematic sexual behavior (Shaw, 2001) needs priority to improve this important area for both individuals with dementia and their caregivers. Despite these limitations, the strengths of this review include

the recognition that all individuals with dementia have unaddressed sexual needs. The review also identified that health professionals need further education to remedy their discomfort experienced when approaching sexual topics and assessment in individuals with dementia.

CONCLUSION

Sexuality in the older adult requires additional research and assessment measures, especially in relation to individuals with dementia and their caregivers. Health care professionals need to be more comfortable discussing this topic and provide assistance to both the individuals with dementia and their care-providing spouses. Additional assessments need to be created to allow for both the individual with dementia and the caregiver to express their thoughts and feelings about associated changes in their sexual frequency and quality of their sexual relationship. Individuals with dementia and their partners still have sexual desires and needs (Dourado et al., 2010).

Health professionals should seek education to assist individuals with dementia and their spouses in coping with changes in intimacy and sexuality as parts of the constellation of behavioral and cognitive decline affecting their relationships. Opportunity would thus be created to decrease care burden and maintain the integrity of sexual relationships. Attempts to decrease caregiver burden and thus maintain sexual relationships should be made a top priority to delay placement in a nursing facility.

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