Sexual Behavior in Men with Dementing Illnesses

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lzheimer's disease and other dementing disorders affect more than 2.5 million persons in the United States. Individuals afflicted with these disorders experience progressive declines in cognitive, behavioral, and social functioning that affect all areas of their lives, not the least of which is sexual functioning. In a

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recent study of 38 spousal caregivers, all participants reported that their partners showed changes in sexual functioning. These same caregivers also indicated that no health-care professionals had asked about sexuality or disseminated information about potential problems with sexuality due to the cognitive disorder.² These results clearly suggest the need for

clinicians and other health-care professionals to raise the issue of sexual functioning with patients and couples who are coping with Alzheimer's disease or other cognitive disorders.

Despite the apparent need for information regarding sexual behavior in persons with dementing illnesses, this is a relatively new field of research. The available literature indicates that sexual difficulties can take various forms, ranging from cognitive sequencing problems during lovemaking to erectile dysfunctions in men with Alzheimer's disease. In

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rare cases, the patient with dementia may engage in sexually inappropriate behavior that requires behavioral management. This article addresses the various ways in which dementing illnesses may affect male sexuality and intimacy. We provide suggestions that will facilitate the assessment and treatment of sexual difficulties in persons suffering from a dementing disorder.

SEXUAL DIFFICULTIES DUE TO COGNITIVE CHANGES

Cognitive changes associated with Alzheimer's disease and other dementias can make it difficult for patients to be sexually intimate. Almost 25% of women caregivers reported that their husbands had difficulty sequencing the steps involved in lovemaking tasks.2 The majority of caregivers (88%) reported feeling distressed about changes in their partner's sexual functioning,3 and dementia may contribute to patients' unawareness of a problem with regard to sexual intimacy. For example, some caregivers report frustration with lovemaking; however, their partners report "no problem" with regard to intimacy.4 Despite these difficulties, many caregivers want to maintain an intimate relationship with their spouse. because they find sexual intimacy to be a source of support, reassurance, and a way of coping with their partner's devastating illness.5

Memory problems and declines in decision-making capacity can interfere with intimacy. Reports from Alzheimer's disease support groups indicate that caregivers find a difficult to make love with a spouse who cannot remember the partner's name. Men caregivers discussed their concern that the Alzheimer's disease patient may not have the capacity to consent to sexual relations; these

caregivers feared that they may be, in a sense, "raping" their spouse. Although the descriptive data indicate that consensual issues are a problem for men in caregiver roles, it remains unclear whether or not women caregivers face these same issues. Despite the inherent cognitive declines in their spouses, a substantial number of caregivers (40%) continued to find their mate attractive,3 and a similar percentage of caregivers (39%) wished to maintain a sexual relationship.2 The desire for intimacy—despite cognitive changes-suggests that many older couples would be amenable to interventions that address successful adaptation to changes in sexuality caused by Alzheimer's disease.

ERECTILE DYSFUNCTION

Recent research has investigated the prevalence of erectile dysfunctions in men with Alzheimer's disease. Zeiss et al found that over 50% of men with Alzheimer's disease had an erectile dysfunction that most commonly coincided with the onset of Alzheimer's disease symptoms and was not attributable to physical problems (for example, diabetes mellitus) or medications.8 Subsequent work in this research group supports these original findings.9 Although not the intention of the research, a recent study published women caregivers' responses to questions about sexual intimacy.10 Six out of seven caregivers indicated that their husbands had difficulty with getting or maintaining erections. These findings indicate that Alzheimer's disease may put men at risk for developing an erectile dysfunction, although the mechanism by which this phenomena operates remains unclear.

Barlow's psychogenic model of sexual dysfunction suggests that cognitive interference

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is responsible for erectile dysfunctions.¹¹ He demonstrated that nondemented men with erectile dysfunctions focused on nonerotic cues in sexual situations. Their attention to nontask-related cues caused them to lose their erections or have difficulty even obtaining them. Lovemaking entails a sequence of behaviors that are not only complex but also rely on timing. It is possible that in men with dementia, diminished attentional capacities interfere with the ability to sustain an erection.

A descriptive study provides preliminary support for attentional explanations of erectile dysfunction in men with Alzheimer's disease.9 In a sample of 19 such patients, men with erectile dysfunctions associated with the onset of Alzheimer's disease tended to lose their erection at the time of intromissionwhen sexual behavior becomes more complex. In this sample, we also noted that the wives of these men reported very satisfactory pre-Alzheimer's disease sexual relationships. It is possible that prior to the Alzheimer's disease, these men may have engaged in very complex lovemaking behaviors, whereas the men without the erectile dysfunction may have had less complex lovemaking behaviors, with the latter group's style being more rote. A rote style may be more resilient to cognitive changes brought on by Alzheimer's disease, albeit less satisfying for the partner.

SEXUAL BEHAVIOR PROBLEMS

Sexually inappropriate behavior in the Alzheimer's disease patient can be a fear for many caregivers, particularly if the behavior occurs in public. Frequently, Alzheimer's disease patients show sexually ambiguous behavior, such as being partially dressed. These behaviors involve no sexual arousal

and reflect disorganization secondary to cognitive impairment. The caregiver may mislabel sexually ambiguous behavior as sexually inappropriate or refer to the patient as "hypersexual." In working with Alzheimer's disease couples, therefore, it is important to get an understanding of what the caregiver means by "inappropriate" sexual behavior.

Sexually inappropriate behavior rarely occurs in dementia patients. A recent study recorded observations of sexually appropriate, sexually inappropriate, and sexually ambiguous behavior in a sample of 30 nursing home residents. The subjects represented a wide range of cognitive impairment, and they were observed during different activities occurring throughout the day. Sexually ambiguous behavior tended to reflect cognitive disorganization and was not associated with sexual arousal. There were very few instances of sexually inappropriate behavior.

Hypersexuality is one of the common behaviors reported by caregivers, although the overall occurrence is low (less than 10%).2 It is unclear whether patients are hypersexualized (greater frequency of arousal, greater frequency of sexual references, more requests for sexual intimacy), or whether caregivers whose desire is declining experience any sexual ove tures as "hypersexual." Furthermore, it is unclear what caregivers mean when they say "frequent": do they mean twice a day, twice a week, twice a month? One study found a small group of Alzheimer's disease couples (14%) to be significantly more sexually active than well couples.3 This group's increased activity was attributable to two Alzheimer's disease couples (men patients) that reported having sex 10 times per month and 14 times per month, respectively. The authors suggested that these two men with Alzheimer's disease experienced hypersexuality. The actual frequency of sexual intimacy was within a moderate range, however. In this situation, it is necessary to determine the couple's pre-Alzheimer's disease frequency of intimacy and compare it to current frequency of intimacy. Only then can "hypersexuality" be defined.

ASSESSMENT AND INTERVENTION

In spite of the sexual revolution of the 1960s, most persons in Western culture are not comfortable talking about sexuality. It is no surprise that the majority of health-care professionals never receive any training around issues of sexuality. It is not necessary to have extensive training in sex therapy in order to ask older adults about sexual functioning, however. Simple questions can be added to a medical assessment. For example, the physician can inform the couple that changes in sexuality can accompany the progression of dementing illnesses and then ask the couple, "How has Alzheimer's disease affected your intimate relationship?" It is common for couples to show their relief that a health-care professional has broached the topic of sexuality. Even if the couple does not have a current sexual issue, they may be more likely to bring up sexuality issues in the future, because they have been given "permission" to be sexual.

Assessment of sexual functioning follows the four-phase framework of the sexual response cycle: sexual desire, excitement, orgasm, and resolution. More detail regarding the sexual response cycle can be found elsewhere (for example, Masters & Johnson¹³), but briefly, sexual desire denotes the individual's urge for sexual activity. Persons low in sexual desire show disinterest

in sexual activity. The excitement or arousal phase includes physiological responses such as erections and vaginal lubrication. Problems in this area occur when there is a disruption of the physiological response. Orgasm is a physiological response that includes the whole body, and diagnosis of an orgasmic disorder only occurs in the absence of desire and excitement disorders. Resolution refers to the body returning to baseline or pre-excitement stage. If the individual has no orgasm, the resolution period could last longer and be accompanied by negative affect, that is, dissatisfaction.

Assessment of sexual functioning includes evaluating the individual's interest in sex, any difficulties with arousal, and problems obtaining orgasm. Sbrocco et al provide a good outline of questions used in routine evaluations of sexual functioning.14 They discuss issues that arise during an interview with older adults, such as age discrepancies between interviewer and interviewee, and they provide suggestions for handling delicate topics, such as how to phrase questions about masturbation and oral sex. Sexual functioning assessments typically include words and language that individuals use on very rare occasions and therefore it can be very useful to practice sking questions about sexuality before entering into a real life assessment situation.

The PLISSIT model (Annon¹⁵) provides a useful intervention framework that is typically used by sex therapists. This model has four levels, the first of which is permission giving (P). This level gives the individual or couple permission to be sexual beings, and the health-care professional communicates acceptance of the couple's sexuality. During the second level, limited information (LI), the professional provides the couple with educa-

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tional information about the changes they are experiencing. The third level, specific suggestions (SS), provides the couple with ideas that might help them adapt successfully to their sexual situation. The last level is the recommendation for intensive therapy (IT) that is usually provided by a professional therapist trained in sexuality issues. Physicians and other health-care professionals can use the PLISSIT framework to quickly address a couple's sexual difficulties. It is best to include caregivers in these assessments because the dementing illness may make a patient's self-report unreliable.

The difficulties some caregivers have in determining whether or not their spouse consents to sexual activity could be addressed during the permission stage. Lichtenberg and Strzepek developed a three-step model to assess an individual's capacity to consent to sexual intimacy within a nursing home. 16 The first two steps of the model are most appropriate for married couples, and they can be used by caregivers who fear that they might be taking advantage of their spouse. Step one evaluates the patient's awareness of the relationship, that is, does the patient initiate sex with the caregiver? Does the patient recognize the spouse? Can the patient state the degree of intimacy that he or she feels most comfortable with? Step two evaluates the patient's capacity to avoid exploitation. Is the patient's behavior consistent with prior beliefs and values? Is the patient capable of saying "no" to sexual invitations?

During the second level of the PLISSIT model, health-care professionals provide the couple with information about their specific difficulty. This could include giving them information about changes in sexuality due to aging, and educating them about erectile problems in men with Alzheimer's disease.

The health-care professional can also facilitate normalization of the couple's difficulties, that is, inform them that the majority of couples facing Alzheimer's disease have a difficult time adapting to changes in sexual functioning. It is important, however, to avoid overwhelming the couple with too much information; this can be achieved by focusing on the presenting sexual problem.

With regard to sexual problems discussed herein, there are several viable suggestions that can be made. Erectile dysfunctions have been successfully treated with vacuum pumps, injections, and implants. These interventions can be frustrating for someone with a cognitive impairment, however. It may be necessary for the partner to assist during the implementation of these interventions. The caregiver may need to aid the patient in other areas of sexual intimacy, such as cases in which the patient has lost some capacity to perform the sequences of lovemaking behaviors. When providing suggestions to a couple, it can be useful to ask the couple what kinds of changes they would feel comfortable implementing. Some suggestions may be well received by some couples, but not by all.

The physician may recommend intensive therapy for couples or individual caregivers whose sexual issues require more than a few suggestions. During the early stages of the disease, couples frequently grapple with changes in sexuality. These couples may benefit from a few counseling sessions in which they discuss ways to continue expressing their fondness and affection for one another, such as increased hugging, kissing, and snuggling. Caregivers trying to cope with their spouses' sexually inappropriate behavior could benefit from individual counseling that identifies the antecedents of the inappropriate behavior and provides the caregiver with

different interventions or coping tools that will decrease the inappropriate behavior. Certainly the work by Barusch suggests that caregivers are at a loss with sexual behavior problems, and there are professionals who can help them.²

CONCLUSION

Dementing illnesses can cause changes in sexual functioning that, if left untreated, can have a deleterious effect on a couple coping with such an illness. Memory problems associated with dementia raise issues of mutual consent for intimacy, and the decline of cognitive processes can interfere with sexual satisfaction for both partners. Erectile dysfunctions are more common in men with Alzheimer's disease than in the normal population, and this disability may prematurely terminate sexual behavior. A small number of caregivers must contend with sexually inappropriate behavior from their spouse, and very few have the resources to cope. Few

clinicians ask about sexual functioning in older couples where one partner suffers a dementing illness, and there is a need to disseminate information about this topic.

It is not necessary for clinicians to become sex therapists in order to address issues of sexuality in older adults. Simply including a few questions about sexual functioning during routine assessments will permit the couple to raise any difficulties they have in this area. Referral may then be arranged if necessary. Clinicians can also improve their ability to assess and help with sexual dysfunctions and concerns by reading, attending workshops and symposia, or taking a seminar in sexuality and aging. Finally, the assessment and intervention techniques discussed in this article can be applied to couples managing other chronic illnesses as well. Aging and illness do not cause individuals to lose their sexuality, and clinicians who are willing to address sexuality issues with older couples can certainly promote the couple's quality of life.

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