
CLINICAL COMMENTS

Sexuality and Intimacy
Between Individuals with Alzheimer's
Disease and Their Partners:
Caregivers Describe Their Experiences

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ABSTRACT. Partners of individuals with Alzheimer's disease (AD) face profound changes in their relationships. Little research has investigated the impact of dementia on sexual function and relationships. This

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paper presents data concerning sexual intimacy within couples affected by AD. Participants' responses were striking for their heterogeneity. Implications are discussed. doi:10.1300/J018v30n03_06 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>>

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INTRODUCTION

Tom and Mary Jones have been happily married for several years. Mrs. Jones described their marriage as a "glorious love affair." Their sex life was like "dessert after dinner." She described her husband as "gentle, sweet, and tender." Prior to the onset of memory problems, Mr. Jones was the initiator of sex; Mrs. Jones followed his lead with interest.

Mr. Jones' memory problems began insidiously. As problems worsened, he would initiate sex and then stop in the middle. He had difficulty obtaining and sustaining erection. Gradually, a good marriage became less than perfect. Mr. Jones' language became punctuated with words like "cunt" and "whore." Mrs. Jones felt resentful of her husband, and less inclined to please him. "I felt like I was just a body to him." Mrs. Jones sought marriage counseling and sex therapy, and both partners participated. She joined support groups, and began using sex toys and new techniques. Mrs. Jones expressed regret that she had not sought help earlier.

Partners of older adults with Alzheimer's disease (AD) and related dementias face a number of challenges. As dementia progresses, these caregivers face fundamental changes in their relationships. Although sexuality is an area in which changes occur, little research has investigated the impact of dementia on sexual relationships. This paper reviews existing literature and presents data concerning sexual intimacy within couples coping with dementia.

Cognitive impairment is often associated with caregiver reports of decline in spousal sexual relationships (Matuszak et al., 2005). This could be due to numerous factors, including caregivers' distress regarding frequent sexual overtures—upset that overtures occur even though the

patient does not recognize the caregiver—and worry about sexually inappropriate behaviors (Davies et al., 1992). Additionally, cognitive impairment may interfere with sequencing of behaviors required for successful intercourse. Caregivers might feel uncomfortable having intercourse with a partner unable to consent (Davies et al., 1992; Redinbaugh et al., 1997). Furthermore, caregivers report experiencing changes in their own sexual function as partners declined. Erectile dysfunction (ED) is common in AD, occurring in as many as 50% of affected males. Indeed, AD may be an independent risk factor for the development of ED (Zeiss et al., 1990). Spouses of dementia patients commonly report that sexual dysfunction precipitated the termination of sexual contact with their partners. Despite all these concerns, there also are caregivers who report a sustained, satisfying sexual relationship despite the dementia diagnosis. Although dementia presents challenges, they do not always disrupt this aspect of loving relationships. The lore of the “hypersexual” dementia patient deserves mention. Despite the widespread belief that individuals with dementia commonly exhibit sexually inappropriate behaviors, research indicates otherwise (Bozzola et al., 1992; Burns et al., 1990; Zeiss et al., 1996).

The goal of this study was to provide a description of caregivers’ experiences with, and emotional responses to, changes in their sexual relationships with partners diagnosed with AD. We feel this is important, given the growing population of individuals with AD who are cared for by their partners. It is our hope that providing the following information concerning sexuality in couples affected by AD will inform clinicians about the importance of these issues and increase their willingness to bring them up with patients.

METHODS

Participants

Participants were 50 couples in which one partner was diagnosed with probable or possible AD (NINCDS/ADRDA criteria; McKhann et al., 1984). Participants were selected from patients (both veterans and non-veterans) evaluated at the Stanford/VA Alzheimer’s Center. Participants were informed of the study during clinic follow-up appointments or telephone contacts. Following diagnosis, participants were asked if they were willing to share their experiences, and they provided informed consent and/or assent.

Procedures

Mental health professionals interviewed partners individually and as a couple; this paper reports on interviews with caregivers. Interviews ranged in duration from ten minutes to one hour. To make participants feel comfortable, a few minutes were spent talking about the early stages of their relationship. Specific questions were then asked from a structured interview (see Table 1). This paper presents responses to the query: "Does your partner initiate sex more or less often than before AD? If there is a change, please describe it." Although other questions were asked, participants provided much more information in response to this query than they did in response to the others. For this reason, we limit our report of responses to this item.

RESULTS

Fifty caregivers (32 females, 98% Caucasian) were interviewed. Of their partners, 42 were diagnosed with probable AD; 6 with possible

TABLE 1. Interview Questions and Sample Responses

Questions to Caregivers	Sample Responses
1. Does your partner initiate sex more or less often than before Alzheimer's?	"... compared to two months ago ... more cuddling and increased affection." "I no longer viewed her as a marital partner. I see her as a child." "I feel like the mother of a 3-year-old, and find it difficult to be aroused." "I feel like I am in a combat zone. He tried to rape me on a few occasions, and I called 911."
2. If there is a change, please describe it.	
Questions to Patients	
1. Have you noticed any changes in your interest in sex or arousal? If "yes," what is the change?	
2. Do you have sexual fantasies more or less often than you did before? If "yes," what are they?	
Questions Asked to Both Patients and Caregivers	
1. Before this [memory] problem began, how were things between you and your partner sexually?	
2. Would you be interested in obtaining some help [with sexual problems]?	
3. What services do you think you would find helpful?	

AD; and 4 with dementia from mixed etiologies. Level of impairment was measured by the GDS (Global Deterioration Scale; Reisberg, Ferris, De Leon, & Crook, 1982). The mean GDS score was 4.6. The mean age of the caregivers was 69.3 years (SD = 8.4). In the following sections we present participants' elaborations in response to the interview question. Additional comments appear in Table 1.

In response to the question, 23 caregivers reported no change, 19 reported a decrease, 5 said that their sexuality had increased, and 6 did not answer the question. Those who reported no change provided a number of qualifiers. Some explained that there had been a decline in sexuality activity even before the onset of AD. For example, two couples stated that they had stopped having intercourse 10 years before the interview, well before the onset of AD. Those who reported a decline often attributed it to erectile dysfunction; in some cases prostate difficulties were noted. One caregiver noted that she suffered from dyspareunia, which resulted in her husband initiating sex less often.

In other cases, the causes of decline were more complex. One caregiver stated that they mutually decided to take a break from sex for three to four months following the spouse's diagnosis with AD, using the time to readjust to a new life with AD, attend support groups and modify life plans. Another caregiver stated that his wife simply declared that she did not want to have sex any more. However, he later realized that she meant that she did not want oral sex, and specifically did not want him to ejaculate in her mouth. He felt that she would have explained her preferences clearly if her memory had not been affected. Another caregiver attributed her husband's lack of initiation to her own lack of interest, which declined as her partner became more self-centered and uninterested in her satisfaction, perhaps as a consequence of AD.

The five caregivers, who reported that their spouse initiated sex more often following diagnosis with AD, provided a number of responses to elaborate. A typical response was one caregiver's explanation that sex was something that she could give to her husband; she would purposefully assume the passive position and prompt the patient to have sex.

DISCUSSION

The goal of this study was to provide a description of caregivers' experiences with, and emotional responses to, changes in their sexual relationships with partners diagnosed with AD. Such information provides an important clinical resource that can challenge stereotypes about the

impact of dementia on intimacy, suggest clinical strategies of potential benefit, and guide development of hypotheses for further research. The most salient aspect of caregivers' responses was their heterogeneity. Reactions included anger, denial, acceptance, satisfaction, humor, fantasy, and feelings of victimization. The great diversity of responses can be explored in terms of each of the three purposes of this article.

First, this diversity challenges stereotypes about dementia. To know that one partner in a couple has a dementia diagnosis does not allow the clinician to predict with any accuracy how that will affect the couples' sexual life and physical intimacy. The couple may continue to enjoy a satisfying sexual life; may have accepted its loss; may be struggling with difficult changes and the problems these present. They may experience this as important in their adaptation to AD, or they may see it as a trivial side story. It is essential that assumptions, implicit or explicit, about "typical" reactions of patients and their partners as dementia progresses be challenged.

That point becomes the basis for clinical guidance suggested by this project. Those working with couples affected by dementia cannot know a particular couple's story unless they ask, in a sensitive way, about the realities and goals for that unique couple. When health care providers keep themselves open to the myriad possibilities, they can become comfortable even in exploring this part of couples' lives. Providers will find that attention to sexual and physical intimacy issues is of great importance for many couples. Sensitive clinicians can provide help through treatment restoring erection for an affected partner, counseling on how to understand the sexual communication of a partner with dementia, and counseling on engaging in simple but satisfying sexual practices that are not overwhelming to an affected partner, etc. Many couples will accept such clinical services with gratitude.

Third, the diversity of findings suggests the importance of further research in this area. Most obviously, we do not know how the quality of a sexual relationship prior to the onset of a dementing illness affects adaptation to dementia. One might hope that better relationships prior to diagnosis would be best maintained, but there are hints that just the opposite might be true (e.g., Redinbaugh et al., 1997). More satisfying sexual relationships prior to diagnosis may depend on sexual sensitivity and creativity that cannot be sustained as dementia progresses. However, our data do not allow a definitive answer on this point, and future research would be invaluable. Other factors that predict who sustains sexual satisfaction, who readily accepts loss of a sexual relationship, and how the presence or absence of a sexual relationship affects other

aspects of caregiving and life satisfaction are additional important research topics. Obtaining answers from such research can become of great importance in designing assessment strategies and clinical interventions most likely to result in increased quality of life for couples struggling with a dementia diagnosis for one partner.

An obvious limitation of the present study is the lack of ethnic diversity among participants. Because 98% of participants were Caucasian, we cannot generalize our findings beyond this group. We hope to include a more diverse range of participants in our subsequent studies, to provide data with broader clinical applicability.

REFERENCES

- Davies, H. D., Zeiss, A., & Tinklenberg, J. R. (1992). 'Till death do us part': Intimacy and sexuality in the marriages of Alzheimer's patients. *Journal of Psychosocial Nursing, 30*, 5-10.
- Litz, B. T., Zeiss, A. M., & Davies, H. D. (1990). Sexual concerns of male spousal caregivers of female Alzheimer's disease patients. *Gerontologist, 30*, 113-116.
- Matuszak, J. M., Sewell, D. D., Rockwell, E., Daly, J. W., & Jeste, D. V. (2005). *Quality of sexual life in dementia patients and their partners*. Poster presented at the 18th annual meeting of the American Association for Geriatric Psychiatry, San Diego, CA.
- McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E. M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task force on Alzheimer's Disease. *Neurology, 34*, 939-944.
- Redinbaugh, E. R., Zeiss, A. M., Davies, H. D., & Tinklenberg, J. R. (1997). Sexual behaviors in men with dementing illness. *Clinical Geriatrics, 5*, 45-50.
- Reisberg, B., Ferris, S. H., De Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139*, 1136-1139.
- Zeiss, A. M., Davies, H. D., & Tinklenberg, J. R. (1996). An observational study of sexual behavior in demented male patients. *Journal of Gerontology: Medical Sciences, 51A*, M325-M329.
- Zeiss, A. M., Davies, H. D., Wood, M., & Tinklenberg, J. R. (1990). The incidence and correlates of erectile problems in patients with Alzheimer's disease. *Archives of Sexual Behavior, 19*, 325-331.

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