

# Practice Concepts

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Little is known about the impact of dementia on sexuality. The attendant cognitive changes that occur in the Alzheimer's patient present the caregiver with many, often conflicting, challenges to a couple's sexual functioning. This case study highlights these issues by describing a man who reported an erectile dysfunction directly stemming from stressful changes that had occurred in his relationship to his wife who had Alzheimer's disease. General themes and relevant hypotheses are derived and clinical practice implications are explored.  
Key Word: Sexuality

## Sexual Concerns of Male Spouses of Female Alzheimer's Disease Patients

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Despite the burgeoning of research and clinical programs related to Alzheimer's disease, practically none has focused on the impact of the disease on sexual functioning. The topic is mentioned only briefly in lay books about Alzheimer's disease (e.g., Mace & Robins, 1981; Cohen & Eisendorfer, 1986; Doernberg, 1989). Teri and Reifer (1986) provided a thoughtful clinical overview of sexual issues, but no empirical data. Zeiss et al. (in press) documented the prevalence of erectile failure in male Alzheimer's disease patients, but did not address other sexual concerns.

Alzheimer's disease has dramatic effects on cognitive and behavioral functioning, which could be expected to have an impact on sexual functioning. The cognitive changes include not only loss of memory, but alterations in other areas such as perception, abstract thinking, language use and comprehension, the ability to problem solve, and the ability to make judgments and decisions (Zarit & Zarit, 1983). Paranoid symptoms and delusions can sometimes occur as well. Social avoidance and fearfulness, as well as irritability, are common. Agitation or verbal and physical aggression, especially toward family members, may develop as the disease progresses.

These changes are typically very stressful for a caregiver. Loss of memory can cause confusion and

result in a patient who is no longer able to be attentive or considerate but may become demanding and aggressive. The inability to communicate, comprehend what is being said, and participate in any meaningful conversation places a severe strain on the relationship. Feelings of loss, anger, and despair in the spouse may also reduce or destroy the sense of intimacy in the relationship.

Apropos of sexual functioning, in the later stages of Alzheimer's disease, these changes may result in patients no longer being able to remember what to do to complete sexual intercourse. It has been hypothesized that the neurological changes of Alzheimer's disease may result in increased sexual desire or disinhibition leading to inappropriate and embarrassing sexual behaviors and offensive remarks. This has rarely been reported, however, (see Mancall, Alonso, & Merlowe, 1985) and may be an unjustified concern (Davies, Zeiss, & Tinklenberg, unpublished).

We are particularly interested in the disruption of sexual intimacy in the couple. Concerns about sexuality have frequently been raised spontaneously in support groups we have been involved in for spouses of patients with Alzheimer's disease, and a variety of specific concerns have been presented. For example, some partners feel distressed about sexual overtures from a spouse who no longer knows their name or at times does not recognize who they are. Others are bothered by frequent sexual overtures (sometimes many each night) from partners who do not remember the episode of sexual intercourse that occurred earlier in the evening.

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Little is known about the frequency of such concerns, about their psychological implications for the caregiving spouse, or about how spouses try to cope with these or other problems. In this paper, we explore issues from the point of view of the male spouse of a female Alzheimer's disease patient.

### Case Description

The client (to be referred to as Carl) was a retired 72-year-old white male who was the caregiver and husband of a patient diagnosed with Alzheimer's disease six years previously. In general, Carl reported coping well with his caregiver role. He was able to maintain social support, was well informed about the disease process, and took advantage of adult daycare services.

Carl had initially entered a group focusing on sexuality in Alzheimer's disease. Because he was reluctant to talk in the group format (where he was often the only man attending) about the specifics of his sexual behavior, particularly his concerns about erectile dysfunction, he was assigned an individual therapist. Carl was able to get and maintain erections when he masturbated (something he started to do more frequently since the onset of his wife's dementia); however, he reported having difficulty both getting and maintaining erections before and during intercourse.

Carl had no history of erectile difficulties prior to his wife's dementia. He reported that he and his wife had pleasurable and satisfactory intercourse approximately two times a month prior to the time she began exhibiting signs of dementia. He had typically initiated sexual contact throughout their marriage. The couple generally had not discussed their sex life with each other, and Carl reported that he and his wife were rather "old fashioned" in that they did not participate in alternative forms of sexual behavior with one another (e.g., manual, oral, or genital stimulation).

Carl observed several dramatic changes in his wife's sexual behavior subsequent to her manifesting symptoms of dementia. The most pronounced change was in the way she began to express her sexual desires and satisfaction. For example, the client's wife began to guide his hand in attempts to get him to stimulate her manually. She would also fondle his penis. Thus, the client was able to identify clear nonverbal indicators of his wife's level of arousal and interest in sexual contact.

Initially, the changes manifested by the patient sexually, as well as her increasing symptoms of cognitive impairment, led Carl to fear that perhaps his wife would begin to display sexual behavior in public. Indeed, one of Carl's initial concerns was that he would not be able to satisfy his wife's emerging sexual demands and that this would increase the possibility of her being sexually inappropriate in public. This concern led to his being anxious about his sexual performance. We hypothesized that this anxiety might be one factor leading to his erectile dysfunction. For example, Carl felt that he had to

orchestrate all of the sexual acts with his wife, such as moving her into the female superior position (which she preferred) after a period of manual stimulation. It was almost always during this phase of lovemaking that Carl would lose his erection. In addition, Carl concentrated a great deal on giving his wife pleasure at the expense of his own sustained arousal. His wife had difficulty manually stimulating him and needed assistance. This was hard for him, but he did assist her sometimes, which resulted in better erections.

In all respects, Carl's performance demand seemed to be self-generated. His wife did not express displeasure about the lack of intercourse and apparently enjoyed being manually stimulated by her husband. Despite her open demonstration of sexual interest, however, Carl often felt, even in the midst of his wife communicating her pleasure and satisfaction, that he was taking advantage of her.

This was perhaps the most significant factor in the client's erectile difficulties, and this concern later became a formidable issue in treatment. So great was his self-doubt in this regard that he sometimes wondered if his interest in having better erections might not even be a selfish concern. Like many other caregivers, he worried that receiving treatment for himself was inappropriate and selfish. The energy that would be required to make treatment gains was seen as not worth it in the face of so many other caretaker concerns and responsibilities. And always this issue came back to his guilt and fear that he was essentially raping his wife by continuing intercourse. Obviously, this feeling of guilt coexisted with a strong need to obtain help, because he had attended a group on sexuality (as one of the only two male members) and readily accepted the referral for individual therapy. Thus, he simultaneously wanted help but felt guilty for wanting it.

The treatment of Carl's problems followed the scheme proposed by Annon (1974) for addressing sexual dysfunctions. This is a powerful heuristic framework in that it provides a way to conceptualize sexual problems and potential interventions that can be used by any sensitive clinician. Clinicians with specific training in the treatment of sexual problems will be at some advantage, of course, particularly with more complex cases; however, many aspects of assessment and treatment can be undertaken by clinicians from a variety of disciplines with good basic skills if they can discuss sexual concerns openly and comfortably. As Annon (1974) describes his goals in developing the model:

What was needed was a . . . flexible and comprehensive scheme that could be adopted to many settings and to whatever client time was available. Such a plan would also have to be adopted by a wide range of people in the helping professions and allow for a range of treatment choices geared to the level of competence of the individual clinician.

In this framework, treatment of sexual dysfunction is targeted in level of intensity to the specific needs of the individual, using the following levels of interventions (from simplest to most complex): permis-

sion giving (P); the provision of limited information (LI); the administration of specific suggestions (SS); and finally, intensive therapy (IT). The sex therapist estimates the level of intervention likely to be necessary and sufficient to obtain treatment goals. If the targeted level does not suffice, then treatment proceeds to the next most intensive level. To conduct intensive therapy, specific training as a sex therapist is usually necessary, but many (if not most) problems can be effectively addressed at earlier levels of intervention. The "PLISSIT" heuristic is clearly applicable for all helping professionals who are confronted with the sexual concerns of spouses of Alzheimer's disease patients.

Because Carl ultimately needed help from each of the levels of intervention, his case serves as an illustration of the kinds of techniques useful at each step. The first level of intervention (permission) was especially helpful in dealing with Carl's uncertainty about whether it was acceptable to seek therapy. He was reassured when he heard from a professional that it was okay to pursue sexual contact with his wife and to get help for his erection problems. Carl also responded well to the limited information (the second level) that could be given to him about the impact of the disease on his wife's functioning, and an explanation as to why he might be having difficulty. In particular, this was helpful in alleviating his concern that his wife might become sexually inappropriate in public because of her Alzheimer's disease.

Specific suggestions (the third level of intervention) were also helpful. For example, one particularly effective method of reducing some of Carl's concerns was with the technique of reframing. He was encouraged to see his wife's ability to express her sexual desires and satisfaction as one of the few means she had left to express affection for her husband; in a sense, her body was "talking." Such physical communication was also reframed as an invitation for Carl to participate. Indeed, there were many behaviors that the wife initiated in the course of a day that were frustrating and hard to understand due to her cognitive impairments. However, when Carl's wife would occasionally take his hand and guide it to her genital area, the message was unambiguous.

In response to these interventions, Carl exhibited some attitude changes and reported feeling more positive about nonintercourse-focused intimate contact. In addition, his concern that she would behave inappropriately in public waned. However, his erectile dysfunction during intercourse remained after 12 sessions. In particular, it was quite difficult to find solutions to two realistic problems: he had to guide sexual activity because she could not remember the sequence of behaviors involved in intercourse, and he received inadequate direct stimulation from her to sustain arousal. These concerns were explored at the level of intensive sex therapy (the fourth level of intervention). Because of the difficulty in changing intercourse behavior with his wife to make it mutually satisfying, he continued to experience concerns about not pleasing her sufficiently (performance anx-

ity) and nagging thoughts about the inappropriateness of intercourse with her (guilt). The resolution that he and the therapist worked on was for him to become more comfortable with the realistic constraints of intercourse, avoid the frustration of repeated failure experiences, and enjoy the mutual nonintercourse sexual pleasuring that she initiated and both enjoyed.

### General Themes

This case highlights several important issues about the sexual behavior of Alzheimer's patients and their spouses. Based on our observations, we offer the following hypotheses. First, it is likely that many spouses of Alzheimer's patients are reluctant to report sexual difficulties and are even more reluctant to seek help. In part, this is because sexuality may be seen as a taboo subject, particularly for an elderly couple. In addition, caregiving partners may be reluctant to raise sexual concerns for fear that such concerns might indicate selfishness, taking advantage of one's partner, or because the spouse believes that sex should have a very low priority. Such conflicting beliefs may lead a partner to judge that addressing sexual problems has no merit or is not worth the effort. Spouses may also feel guilty that they are not doing enough for their partners in general. This belief may generalize to either concerns about not being able to sexually fulfill their partners sufficiently or the belief that attending to their own sexual needs is somehow wrong and inappropriate.

In addition to these fears, which we hypothesize contribute to reluctance to address sexual issues, the disease process can lead to changes in the manner in which sexual desires are manifested, as well as in arousal patterns. As a result, significant and unexpected alterations often occur in sexual behavior in the dyad. In response, the spouse may need to use nonintercourse-oriented activities for sexual satisfaction (e.g., masturbation, mutual manual stimulation). Spouses of Alzheimer's patients may also need to find pleasure in intimate, but covertly sexual contact, such as massaging, touching, and hugging their partners (Teri & Reifer, 1986). In addition to the realistic difficulties of renegotiating sexual patterns when one partner is demented, the problems posed in changing sexual behavior set the stage for possible increased experience of performance demands for the caregiver. In trying to guide the flow of sexual behavior, the nondemented spouse may take on a dysfunctional role described by Masters and Johnson (1970), "the involuntary assumption of a spectator's role during active sexual participation."

Finally, other realistic concerns are not exemplified in this particular case, but are of potential importance to a caregiving spouse. For example, advanced dementia may make it impossible for the patient to sustain even the minimum concentration or attention for sexual intercourse or manual stimulation. The time may come when it is indeed impossible to engage in sexual behavior with a seriously cognitively impaired spouse. In addition, the very ad-

vanced Alzheimer's patient may no longer be sexually attractive to his or her partner because of changes in appearance, grooming, and continence.

So far, we have discussed concerns relevant to a male caregiving spouse. On the one hand, we expect some of the changes that occur in sexual intimacy that have been highlighted by Carl's case to be generic and apply in most cases (e.g., concerns about selfishness). On the other hand, we would expect some gender-specific effects to occur. For example, in Western society, men are generally perceived as more sexually aggressive, with women setting limits and being perceived as less interested in sex. The lifetime impact of these roles may be destructive in a wide variety of ways (e.g., Zilbergeld, 1978; Barbach, 1975). When Alzheimer's disease is present, we find that these sex-typed roles have a predictable impact: regardless of which partner has Alzheimer's, it is likely that the female partner will be seen as losing interest in sex, whereas the male partner will not.

As in the case of Carl, the male partner may be vulnerable to fearing that a wife with Alzheimer's is being forced into sex if she cannot consciously and verbally agree to sexual activity. Other male caregivers might become interested in finding other sexual partners, but feel guilty or distressed about this interest. This may be especially distressing if the impaired wife expresses paranoid concerns about infidelity, as does often occur.

With female caregivers, in our experience, a different concern emerges: they are more likely to worry about rejecting the advances of a husband with Alzheimer's disease, partly out of concern for wounding his pride. These concerns, we hypothesize, are a direct result of Western double standard sexual morality applied in the context of dementing illness. The underlying assumptions are that men (whether or not they have Alzheimer's) will continue to want sex, whereas women (whether or not they have Alzheimer's) will be less interested in sex and only want sex if the right conditions for intimacy, attraction, etc. are met.

In summary, cases such as the one described above raise a series of questions about the prevalence, content, and phenomenology of sexual problems in Alzheimer's patients and their spouses. We need more information, from research and clinical programs, about common sexual concerns of spouses of Alzheimer's patients, both from spouses that are functioning in what they consider to be a normal fashion and from spouses who are experiencing sexual difficulties. We also need to understand more about the relationship between the role of sexuality in the relationship before one spouse develops Alzheimer's disease and how couples adapt

their sexual behavior in response to the disease. Finally, we need to continue to develop effective means of helping spouses of demented patients who seek help for their sexual problems.

The first step that should be taken in this regard is to acknowledge explicitly, in both the lay and professional literature, that Alzheimer's disease is likely to have a significant effect on sexual behavior, but that both patient and partner will still have sexual needs and feelings. Changes in sexual behavior are likely to be experienced by the spouse as stressful and require some kind of adjustment. When partners of Alzheimer's disease patients have greater access to information about sexuality and dementia, they will be more willing to share their own sexual concerns and thus open a dialogue between spouses and helping professionals.

In addition, more professionals need to be trained to discuss sexual issues openly and sensitively. This is partly a matter of training in interview techniques, but it also involves challenging one's own discomfort and understanding one's own biases about sexuality, particularly sexuality in elderly or cognitively impaired people. For example, workshops involving role playing in small groups how to interview an Alzheimer's patient or their caregiver can provide experience. Such role playing can vividly highlight one's own emotional response in a safe context for discussion. Leaders of Alzheimer's support groups are in a position to make particularly important contributions by enhancing their knowledge about and comfort with discussion of sexual intimacy and Alzheimer's disease.

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