

'Til Death Do Us Part: Intimacy and Sexuality in the Marriages of Alzheimer's Patients

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Despite the dramatic burgeoning of research and clinical programs related to Alzheimer's disease (AD), little attention has been paid to the impact of the disease on sexual functioning. Teri and Reifler (1986) have provided a thoughtful clinical overview of sexual issues, pointing out that sexual problems and concerns about sexuality may be extremely important for patients and caregivers.

Concerns about sexuality are frequently raised spontaneously in support groups for spouses of patients with

AD. A variety of specific concerns have been presented. 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 an episode of sexual intercourse that occurred earlier in the evening. Another concern is fear of inappropriate sexual behavior, such as patient who exposes themselves or masturbates in public. Despite these concerns, many couples would like to maintain intimate sexual contact. This allows them to retain some aspects of their marital closeness despite the tragic losses of AD.

We have been interested in how couples approach all the dilemmas posed by AD, and the purpose of this review is to share some of our ideas and experience. We begin with the observation that spousal caregivers have one of the world's toughest jobs, if not the toughest. They must provide a variety of instrumental and nursing care tasks for a beloved person who is changing inex-

orably. They must remain calm and patient when their spouse is irritated, confused, upset, demanding, or otherwise difficult. They must manage their own grief and sense of loss while still maintaining constant devotion to the source of that loss. Why do spouses take on and maintain such a draining, and often discouraging, role? It seems that the role of the marriage in sustaining caregiver commitment is crucial. Current elders are part of a cohort who promised to love and stand by each other "in sickness and in health, 'til death do us part," and their low divorce rate underscores how seriously they took those vows.

Mosenko (1989) has studied caregiver frustrations and gratifications, concluding:

The meaning of the caregiver role is apparently more important in predicting caregiver burden than the duration or severity of patient symptoms. Perception of continuity in marital closeness lends meaning to the caregiver role. . . . Their expression of marital closeness imbued the caregiving

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FIGURE 1
Summary of What Has been Learned In Studying Sexuality and Alzheimer's Disease

Erectile failure is a high frequency problem in men with Alzheimer's disease.

Issues regarding physical closeness may differ for women who are caregivers compared with men who are caregivers.

Physical touch is a basic human need and an important way of communicating caring when one partner has Alzheimer's disease.

Inappropriate sexual behavior is an infrequent problem in patients with Alzheimer's disease.

role with meaning; and for these wives, continuing to express lifelong marital affection was a source of support as well as source of stress."

At one time, most in this cohort (especially among women) equated sexuality with marriage. Marital closeness provided the context for acceptable enjoyment of sexual activity, and sexual sharing was expected in marriage. Some even spoke of intercourse as a "marital responsibility." Physical intimacy went hand in hand with emotional intimacy and commitment to lifelong mutual caregiving.

When AD strikes, a spouse with these commitments is faced with a situation that, in terms of sexuality at least, is fraught with problematic contradictions. The marriage plays a vital role in the commitment to caregiving, and part of marriage is sexual intimacy. Yet emotional intimacy, lost in AD, is also a condition for acceptable sexuality. How do caregivers handle the conflicts regarding sexuality? The following reactions are commonly described; they cover a wide spectrum in terms of level of interest in continued sexual contact.

Some spousal caregivers are no longer interested in sexuality or physical intimacy. Common reasons given for this are the patient's inability to identify the spouse or remember the spouse's name, the patient's incontinence or poor personal hygiene leading to physical distaste on the part of the spouse, and the change in relationship roles such that the caregiver feels more like a parent than a spouse. Still others fear sexual

arousal that will later leave them with feelings that "have no respectable outlet."

Other spousal caregivers express an interest in maintaining sexual activity or physical intimacy, but feel frustrated by problems that arise. For example, the patient may forget the sequence of events involved in intercourse and be unable to participate as a sexual partner, or the spousal caregiver may be too physically tired to have energy for sexuality, or the spouse may feel guilty or embarrassed about initiating sex with a partner who cannot clearly consent or refuse.

Other caregivers describe feeling that sex per se is irrelevant to them, but that they miss being held, kissed, told they are loved, etc. These caregivers often enjoy quiet aspects of caregiving, such as brushing the patient's hair or sitting on the couch together while watching a movie.

At the other end of the spectrum, some spousal caregivers maintain sexual activity or physical intimacy with a sense of satisfaction. These caregivers feel that sex is good for them, for example saying, "It's one thing we can still do as a couple, one way we still feel close." It is unclear how advanced AD can become while still allowing the spouse to feel this sexual, emotional bond.

We have been interested in studying what factors might be related to the different patterns of response in different couples. Research is still in its early stage and there are few definitive an-

swers as yet. However, we have generated some research data and clinical experience directly related to these issues. These findings are briefly summarized in Figure 1 and described in more detail in the following sections.

What We Have Learned

AD and Erection Problems. Erectile failure is a high-frequency problem among men with AD. In a recent study of 55 men with Alzheimer's disease, 53% reported loss of erection concurrent with the onset of AD symptoms (Zeiss, 1990b). Loss of erection was not related to degree of cognitive impairment, age, depression, medication use, or concurrent physical problems. The incidence of erectile problems found in this sample is higher than that reported in studies of similarly aged nondemented men. This evidence suggests that there may be an elevated incidence of erectile failure in patients with AD as a primary problem not attributable to other age-related factors.

What we do not know is how AD might affect erectile functioning. It is conceivable that there could be a direct effect, with the central nervous system deterioration of the disease disrupting the necessary pathways mediating arousal or erection. Alternatively, there could be indirect psychological effects. A man with early AD may feel that he is no longer a true "husband" or appropriate sexual partner. This view may be shared by the wife as well. Or the couple may focus their attention on making other, more salient adaptations to the disease (such as dealing with its impact on the extended family or their own financial resources). The stress of these adaptations may preclude having the emotional energy to continue an active sexual relationship. Preliminary work with a small number of AD patients with erectile failure and their partners in sex therapy has shown good results, suggesting that psychological factors are important in at least some cases. Further research is needed to expand our knowledge in this area.

Physical Closeness for Caregivers. In Western society, men are generally perceived as more sexually aggressive, with women perceived as setting limits and being less interested in sex. The

impact of these roles may be destructive in a variety of ways (Barbach, 1975; Zilbergeld, 1978). When AD is present, our experience is that these sex-typed roles have a predictable impact: regardless of which partner has AD, it is likely that the woman will be seen as losing interest in sex, whereas the man will not.

Male spouses may be vulnerable to fears that a wife with AD is being forced into sex if she cannot consciously and verbally agree to sexual activity. They may be troubled by feelings of guilt that they are taking advantage of or essentially raping their wives by continuing intercourse.

A husband may experience discomfort with his wife's disinhibition, especially if it results in changed initiation patterns and sexual behaviors. This may lead to fears that if he is unable to satisfy his wife's emerging sexual demands, there will be an increased possibility that she will display inappropriate sexual behaviors in public.

In women there is a close linkage between physical and emotional intimacy. Sex is fine while the husband with AD still recognizes his wife. When that ends, sex can become conflictual and women may want to avoid sexual activity. However, female caregivers often feel guilty about rejecting the advances of a husband with AD. This seems to be partly out of concern of depriving him sexually and wounding his pride, and is partly fueled by the underlying assumption that it is the wife's "marital responsibility" to provide sex if the husband wants it.

Touch and Emotional and Physical Well-Being. Touch is probably the best way to show we care. It elicits a sense of generalized relaxation that makes caring and sharing a natural, easy result (Ridzon, 1989). Montague (1971) stresses the importance of touch in the neonatal period and the relationship between touch and health throughout the life span. Zefron (1975) states, "Observations have given a scientific basis for what we have instinctively known: human beings need to be cuddled, stroked, and touched to be healthy and survive."

Weiner and White (1982) link depression with sexual expression and

observe that in the older person, depression represents a loss of self, whereas the opportunity for sexual expression represents an affirmation of self. A review of the medical research literature is remarkable in its lack of writings regarding the need for and importance of touch in individuals with AD. The nursing research literature has dealt more with this topic, emphasizing the importance of touch for patient self-esteem and well-being (Burnside, 1981; Copstead, 1980; Hollinger, 1986; McCorkle, 1974; Vortherms, 1991). Clinicians have also emphasized the important role of touch in maintaining sexual intimacy and caring in a marital relationship.

Touch can be used in a variety of ways to calm, reassure, and provide a sense of being valued and cared for. Massage, stroking, holding hands, hugging, and kissing are a few of the ways that can be used to communicate with AD patients. For Alzheimer's patients who suffer multiple losses (eg, loss of memory, loss of self-esteem, and loss of the ability to express themselves), touch as a means of communicating care, intimacy, and concern is doubly important.

Spouses of AD patients may also need to find pleasure in intimate, but not overtly sexual, contact. If they are not sexually active and are no longer sharing a bed with their spouse, it is important to think about how to have this kind of touch. Feeding, combing the patient's hair, sharing, and massage are some means of achieving this. Bathing is another, but often patients in the more advanced stages develop a fear of bathing and other means need to be considered. Setting aside time each day for intimate contact may be helpful.

When a partner is in a nursing home, special problems arise. Often there is no provision for privacy, and staff may feel uneasy acknowledging patients' and caregivers' sexual needs. Taking the patient for a ride or walk or finding a quiet corner in a patio garden or waiting room where one can sit quietly, hold hands, or listen to music can help maintain a sense of privacy and sharing within an institutional setting. It is important for health-care providers to recognize that AD patients and their part-

ners have sexual concerns and needs. Consideration of sexuality is integral to the treatment of the total person. If it is possible to enhance a patient's life by addressing these needs, it is a tragedy not to do so.

AD and Inappropriate Sexual Behavior. Caregivers often express concern that AD patients will become inappropriate in their sexual behavior or expression of sexual feelings. Sometimes these fears are fostered or supported by popular literature on AD. For example, Powell and Courice (1983), in their discussion of "sexual communication," present only information on clear, overt instances of inappropriate behavior; the implication, of course, is that these are common. The following quote exemplifies their message:

I have a friend whose father has Alzheimer's disease. He's been living with her and her family for a few months, and when she calls me long distance, I tell her jokingly that the telephone company is going to cut us off because the conversation sounds obscene. She says that her father is constantly masturbating—anytime, all the time, anywhere in the house. It makes her very angry (Powell, 1983).

However, other sources convey much less concern. For example, Mace and Rabins (1981) minimize this concern:

Sometimes brain damage will cause a person to demand sexual activities frequently or inappropriately. But much more common than actual inappropriate sexual behavior is the myth that "senile" people will develop inappropriate sexual behaviors. One wife who brought her husband to the hospital for care confessed that she had no problems managing him but that she had been told that, as he got worse, he would go into his "second childhood" and start exposing himself to little girls. There is no basis to this myth. Inappropriate sexual behaviors in people with dementing illnesses are uncommon (Mace, 1981).

Our data from another recent study (Zeiss, 1990a) support Mace and Rabins' position. In that work, we felt it was important to separate inappropri-

FIGURE 2
Illustrations of the PLISSIT Model for Use With Alzheimer's Disease Patients and Caregivers

Abbreviation	Level of Intervention	Example of Intervention
P	Permission	Accept caregiver's interest in responding to sexual initiation by a spouse with Alzheimer's disease as reasonable.
LI	Limited Information	Educate about physiological changes associated with normal aging (eg, loss of vaginal lubrication) as opposed to changes due to dementia.
SS	Specific Suggestions	Suggest sensate focus exercises during early dementia to reduce Alzheimer's disease patient's performance anxiety.
IT	Intensive Therapy	Psychotherapy regarding problems of guilt in a caregiver who is conflicted regarding sexual behavior.

ate versus appropriate sexual behavior and inappropriate nonsexual versus sexual behavior. For example, touching one's partner's breast in public is inappropriate, but touching it in private is not. Although such behavior is not inappropriate, it may be upsetting to a caregiver who is no longer interested in sexuality, and the caregiver may therefore incorrectly label it as inappropriate. Mistaken labeling may also occur when behavior is incorrectly labeled "sexual." For example, a patient may go out with his fly unzipped and his genitals partially exposed; however, this usually is not exhibitionism but simply a consequence of poor cognitive function and inability to carry out reasonable personal care. True sexually inappropriate behavior consists of overt acts with a sexual intent or meaning; for example, masturbating in public, making sexual comments to health-care providers, or reaching out to fondle someone other than the spouse.

For this research project (Zeiss, 1990a), we observed Alzheimer's patients in a locked residential facility and a day care program to study the

actual frequency of such sexually inappropriate behaviors. Having observed more than 30 patients in a variety of activities, at all times of day, and at varying levels of severity of the disease, we observed very few instances of sexually inappropriate behavior. There were some instances of nonsexual inappropriate behavior (eg, being partially dressed in a public area). There were more instances of sexually inappropriate behavior (eg, pressing on genitals in public) among demented non-AD patients, such as alcoholic dementia patients.

We also asked spousal caregivers to report on whether sexually inappropriate behavior occurs at home or in community settings. No caregiver reported instances of such behavior, and few caregivers described worry that it will occur. However, some caregivers initially labeled behavior as inappropriate when it actually was appropriate, but upsetting for the caregiver.

Thus, it appears that concerns in this area are overblown. There certainly may be patients who do behave inappropriately (most health-care providers can

remember one or two salient cases in their experience), but they appear to be rare and overemphasized in many popular writings about AD.

Conclusions and Implications

We have described current knowledge and raised questions about the prevalence, content, and phenomenology of sexual problems in AD patients and their spouses. We need more information, from research and clinical programs, about common sexual concerns of spouses of AD patients. We also need to know more about how the role of sexuality in the marriage before one spouse develops AD affects the couples' sexual behavior in response to the disease. We need to continue to develop effective means of helping spouses of demented patients who seek help for their sexual problems. Additional information is needed on important questions regarding how caregivers sustain meaningful marriages, such as: What are the gratifications as well as the frustrations in maintaining closeness in the marital relationship when a spouse as AD? How do caregivers and patients meet their needs and what are the consequences of unmet needs? What feelings underlie aspects of sexuality, such as masturbation, touching, and genital sex in this population?

The first step that should be taken in this regard is to acknowledge explicitly, in both the lay and professional literature, that AD is likely to have a significant effect on sexual behavior, but that both patient and partner will still have sexual needs and feelings. The spouse is likely to experience stress resulting from changes in sexual behavior and will require some kind of adjustment. When partners of AD patients have greater access to information about sexuality and dementia, they will be more willing to share their own sexual concerns and open a dialogue with 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 cog-

natively impaired people. Workshops on how to interview an AD patient or their caregiver about sexuality, conducted with role playing in small groups, can provide valuable experience. Such role playing can vividly highlight one's own emotional responses in a safe context for discussion. Leaders of AD support groups are in a position to make particularly important contributions by enhancing their knowledge about and comfort with discussion of sexual intimacy.

Professionals could also offer useful clinical interventions without explicit training in the conduct of intensive sex therapy. Annon (1974) has proposed a powerful heuristic framework for addressing sexual problems that provides a way to conceptualize sexual problems and potential interventions that can be used by a 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 schema that could be adapted 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 concerns is targeted in level of intensity to the specific needs of the individual, using the following levels of interventions (from simplest to most complex): permission giving (P); the provision of limited information (LI); the administration of specific suggestions (SS); and intensive therapy (IT). Some specific examples of such interventions are shown in Figure 2. The therapist estimates the level of intervention likely to be necessary and sufficient to obtain treatment goals. If the

Sexuality and Alzheimer's Disease KEY POINTS

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1. Alzheimer's disease (AD) is likely to have a significant effect on sexual behavior, but both patient and partner will still have sexual feelings and needs.
2. Research has shown that a high proportion of men with AD develop erection problems, but causes of their erection difficulties are not understood.
3. Research has shown that inappropriate sexual behavior in AD patients is uncommon, although it can be very troubling to the family and health-care provider if it occurs.
4. More professionals need to be trained to discuss sexual issues openly and sensitively with AD patients and partners and to offer useful clinical suggestions.

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 applicable for all helping professionals who are confronted with the sexual concerns of spouses of AD patients.

For example, it may often be useful to give spouses permission to have their needs for cuddling and physical closeness met and to allay their fears that this will stimulate the patient and lead to sexually inappropriate behavior. At the next level, professionals could provide information about normal age-related changes in sexual functioning, special problems among AD patients and their spouses, and the range of solutions couples have worked out to handle these problems. Furthermore, specific suggestions could be offered when caregivers are upset by a partner's sexual initiation. Suggestions could include distracting the patient or diverting the sexual initiation to a more acceptable level of physical touching. For some couples, sex therapy may help re-establish erectile function and intercourse in early dementia cases where continued sexuality is a mutual goal.

In addition to dealing with caregivers

and couples, health-care professionals can provide useful skills at other societal levels. For example, nurses can play an important role in urging long-term care facilities to provide private settings for spouses to continue physical intimacy after placement of the patient. Nurses in home health-care settings can design assessment and intervention procedures to be sensitive to sexual concerns, making this a routine part of an evaluation. Finally, nurses can become trainers for other staff or volunteers, raising the general level of awareness and comfort with sexual issues.

Although it is not part of the nurse's role to be a sex therapist, nurses are often the primary providers of ongoing care to AD patients and their families. This places them in a unique position to provide documentation and conduct research that will lend further insights not only into sexuality in AD, but also into the entire range of sexuality of older adults.

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