

Sexuality and Intimacy in Alzheimer's Patients and Their Partners

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Geriatric Sexuality remains one of the more sensitive and controversial issues to be confronted in today's clinical setting. Research indicates that older adults continue to be sexually active well into later life. Older adults with dementing illnesses experience deleterious changes in sexual functioning that can affect their quality of life. However, few health care professionals ask older adults about their sexual functioning. This paper addresses means of fostering acceptance by professionals and families and creating an environment that nurtures sexuality in couples coping with dementia.

KEY WORDS: sexuality; intimacy; sexual dysfunction; Alzheimer's disease.

Several studies have dispelled the myth that older adults are not sexually active. The Kinsey reports (1,2) found that 80% of persons aged 60 were sexually active. More recent literature on sexual functioning in adults generally finds that while there may be some modest declines in sexual functioning as people age, sexual activity within a couple remains fairly stable across middle and later life. Cessation of sexual activity in a heterosexual couple is usually due to the attitudes or physical condition of the male partner (3). Hence, two common patterns of sexual activity in older adults have emerged: 1) where the couple maintains a steady level of sexual activity and 2) where a dramatic decline or sudden cessation of sexual activity occurs. Frequently, illness associated with erectile dysfunction is the cause of the second pattern; i.e., older

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couples act as if they believe that erections are necessary for sexual activity to continue (4). When the male partner remains healthy, couples do typically continue sexual activity with only modest changes from earlier activity levels and satisfaction. Illness of the female partner has much less influence on sexual activity patterns.

Although the general literature on aging supports the conclusion that older adults commonly are sexually active, there is much less information on the impact of dementing illness on sexual function, activity patterns, and satisfaction.

SEXUAL DIFFICULTIES DUE TO COGNITIVE CHANGES

Alzheimer's disease (AD) and other dementing illnesses affect over 2.5 million people in the United States (5). People 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 recent study of 38 spousal caregivers, all participants reported that their partners showed changes in sexual functioning (6). These same caregivers also indicated that no health care professionals had asked about sexuality or disseminated information about potential problems with sexuality due to cognitive disorder.

Although there is a growing body of knowledge regarding the impact of dementia on sexuality, many questions remain. Recent evidence suggests that inappropriate sexual behavior in AD patients is a rare event (7), but sexual dysfunction in male patients may be greater than that found among similar aged healthy men. Zeiss et al. (8) found that over 50% of men with AD reported an erectile dysfunction that most commonly coincided with the onset of AD symptoms and was not attributable to physical problems or medications.

The attendant cognitive changes that occur in the Alzheimer's patient present many, often conflicting challenges to a couple's sexual functioning. The available literature indicates that sexual difficulties in AD can take various forms ranging from cognitive sequencing problems during love making to erectile dysfunction in men with AD. 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 (9). 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 (8). Memory problems and declines in decision making capacity can interfere with intimacy. Male caregivers express concerns that the AD patient may not have the capacity to consent to sexual relations, these caregivers fear they may be, in a sense, "raping" their spouses (10).

Despite these difficulties, many caregivers want to maintain an intimate relationship with their partner because they find sexual intimacy to be a source of support, reassurance, and a means of coping with their partner's devastating illness (11). The more the spouse can retain the ability to view the patient as a person with whom to enjoy sexuality the more likely the relationship can endure with some quality. Research has indicated that patients are more likely to remain in the home setting when the caregiver feels that there is some reciprocity gained from the relationship.

Sexuality and intimacy play an important role in meeting this need. For example, one caregiver described the following experience at a fairly early point in her husband's illness. "He put his arm around my shoulders, and we stood together looking off into our dark anniversary night . . . the motel bed, massage oil, Baroque tapes, a book of short stories, a breakfast of lingonberries and Swedish pancakes, and tomorrow's day at the beach . . . all those many pleasures still before us" (12).

The onset of the illness does not erase sexuality, but rather alters the way in which love is given and received. For some patients, remaining sexually active provides one of the few remaining ways in which they feel they can maintain their role identity and provide something of value to their partners. As one patient poignantly put it, "I can no longer provide an income, make decisions, or take care of things; this is the only thing I still have that I can give to my wife."

Studies have identified links between depression and sexual expression. Depression is not uncommon for Alzheimer's patients early in their disease process. Many caregivers also struggle with depression. The primary effect of depression on sexuality is reduced sexual interest or desire. Depression also can affect physiological response to stimulation—erection in men and lubrication in women. On the other hand, sexuality can sometimes be a source of positive emotional and physical experience that helps to ease depression, as shown in the following example: "Such a blessed release crying together, sharing the same sorrow at the same time. A moment to cherish, not to work so hard to avoid. 'My darling man,' I said. 'It's sad to leave, Julian. It's sad what's happening to our life. But we're in this together. We'll do the best we can.' His body softened and he let me hug him. We drove home in silence . . . And that night in bed, we held each other close in the dark" (13).

BARRIERS IN ADDRESSING SEXUAL ISSUES

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 AD. Health care professionals however, have

not responded adequately to this need. In support groups where the topic has been addressed the response of caregivers has been "It's about time somebody brought this up." In the words of one caregiver, who shared her concerns in response to sympathetic questioning from a medical care provider:

"And out it all tumbled. I cried and blubbered and sputtered the whole story, how my husband and I had been married thirty-two years, how we had always had a gratifying sex life, how sex had been important and gratifying in our lives. Now intercourse hurt. I avoided sex. I made excuses. I got it over with as fast as I could. It had never been like this, I said. More tumbled out. I told him I was hardly interested in sex lately. No libido. I told him I had had breast cancer and a mastectomy four years ago, but having one breast wasn't why. . . . What I realized suddenly sitting there on his examining table, was how much it still mattered. And how much I had given up. Perhaps I didn't have to lose this part of my life so soon" (14).

Health professionals frequently assume that once a patient is institutionalized, sexual problems or issues are resolved or disappear. Placement does not automatically end the sexual connection between a couple or the need for intimacy in a patient. Residents and their partners have the right to seek out and engage in sexual expression, and be given privacy to carry on intimate relationships.

Many health professionals do agree that AD patients have a right to sexual expression. However, cultural values, personal beliefs, and inadequate training provide obstacles for clinicians to address confidently their patient's sexual needs. In spite of the Sexual Revolution of the 1960s, most people in Anglo-European culture are not comfortable talking about sexuality. Among other cultures, it can be even harder, even to the point that the discussion of sex within one's family is taboo; it simply is not discussed openly. The subject of sexuality in older adults is especially difficult to confront due to the conjunction of two strong beliefs: 1) sex is for the young, and 2) sex is for the cognitively intact.

Compounding the cultural attitudes, the often unconscious personal beliefs and moral codes clinicians adhere to regarding sexuality may also conflict with their stated professional beliefs. Studies reveal that undergraduate and medical students feel uncomfortable when picturing elderly couples kissing, masturbating, or having sexual intercourse, thereby identifying aging with asexuality (15,16).

The topic of sexuality has frequently been omitted or minimized in the training of service providers. For example, national accrediting bodies for schools of medicine and psychology do not require training in sexuality for accreditation. In the State of California, Psychologists are required to have 10 hours of training in human sexuality to be eligible for licensure, but there is no requirement that this include consideration of aging and sexuality. This lack of

training has in turn, led to a relative lack of awareness of the importance of sexual issues in clinical settings with AD patients and their partners.

More health 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 the elderly or cognitively impaired. One exercise that can be used to assist in examining one's set of permissions for expressing sexuality is shown in Table 1. Once you can understand your own sexual values, and can separate them from those of your clients, you can begin to work on increasing skills for interviewing clients about sexuality. Specific recommendations for interviewing content follow in the next section.

Table 1. Exercise in Sexual Permission Systems

	Permission	Prohibitions
WITH WHOM is it OK and not OK to have sex?	(e.g. your spouse, all living beings, people with whom you are "in love," yourself?)	(e.g. your friend's spouse, patients/clients, age differences, cognitively impaired?)
WHERE is it OK and not OK to have sex?	(e.g. in bed, in your office, in a sleeping bag? or them in yours?)	(e.g. in a nursing home, in your child's bed?)
WHEN is it OK and not OK to have sex?	(e.g. in the dark, in sunlight, when he's/she's sweaty, when no one can hear you?)	(e.g. when you're drunk/on drugs, when others can know, when you're being forced or coerced?)
WHAT is OK and not OK to do in having sex?	(e.g. have sexual intercourse, kiss, rub each other's bodies, masturbate?)	(e.g. tie each other up, use oil or whipped cream, have anal sex?)
WHY is it OK and not OK to have sex?	(e.g. mutual and consenting, to commit/share something significant and meaningful for each of you?)	(e.g. focusing on your needs only, power or control driven?)

Each of us has a rather elaborate and quite specific set of permissions that either gives permission or denies it for expressing our sexuality. While the development of these dos and don'ts is itself a fascinating source to explore, the focus of this exercise is simply on identifying and cataloguing, our own system for self-assessment and self-reflection.

When doing this exercise, suggestions are offered to get you thinking. We don't *endorse* these permissions or prohibitions; they are just to get you started. You need to supply your *own* thoughts and ideas about permissions and prohibitions in each category.

After considering your permissions and prohibitions, ponder and compare the same areas for your patients or clients. Consider how your practice may be affected.

ASSESSMENT OF SEXUAL CONCERNS

Assessment of sexual functioning follows the four phase framework of the sexual response cycle: sexual desire, excitement, orgasm, and resolution. Sexual desire denotes the individual's urge for sexual activity. Excitement includes physiological responses such as erections and vaginal lubrication. Orgasm is a physiological response that includes the whole body. 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 feelings (e.g., discomfort, dissatisfaction) (17).

Assessment of sexual functioning includes evaluating the individual's interest in sex, any difficulties with excitement, and problems obtaining orgasm. Sbrocco, Weisberg, and Barlow (18) provide a good outline of questions used in routine evaluations of sexual functioning. They discuss issues that arise during an interview with older adults (e.g., age discrepancies between interviewer and interviewee), and provide suggestions for handling delicate topics (e.g., how to phrase questions about masturbation and oral sex).

In our experience, the questions suggested by Sbrocco, Weisberg, and Barlow need some modification, but not much, to fit the circumstances of couples where one partner has a dementing illness. Initial questions should establish that the person is willing to discuss sexual issues and concerns. The interviewer should validate that this will likely be uncomfortable, but assure the person being interviewed that his or her wishes concerning level of disclosure will be respected.

If the person being interviewed is the partner with Alzheimer's disease, the interviewer should of course avoid asking detailed questions regarding memory of specific information (e.g., "When did you first notice that you had a problem maintaining erections?"). Questions should emphasize the feelings the patient has about sexuality and the hopes he or she has for the role it might continue to play in his or her life. General description of problems he or she has experienced is also appropriate.

If the person being interviewed is the non-demented spouse, more detailed questions may be helpful, after an initial period of rapport building. Discussion of the general impact of Alzheimer's disease on various aspects of sexual activity and the sexual relationship is generally a good way to begin. As the interview progresses, it is helpful to get information about the level of desire experienced, ranging from aversion to sex to strong desire. Questions in this section of the interview should focus on sexual thoughts, feelings, and urges. Sometimes this is confusing for the person being interviewed, who will respond regarding physical manifestations of excitement (i.e., erection or lubrication), rather than about the internal, emotional experience of desire. When this hap-

pens, it is important to re-orient the person being interviewed, perhaps by asking about sexual fantasies or dreams to emphasize the kind of information you are trying to obtain. If the level of desire is low, information on desire before the onset or progression of Alzheimer's disease is helpful—some couples have always had sexual difficulties, and it is important not to attribute all problems to the disease (this will hold true in all the categories to follow).

When the interviewer discusses the excitement phase, questions about physical manifestations of arousal are appropriate (maximum degree of erection, ability to maintain erection, vaginal engorgement and lubrication, etc.). In this section of an interview, we strive to get enough information to generate a clear understanding of a typical sexual scenario—who initiates, kinds of behaviors used to heighten arousal, and the level of physical arousal obtained and maintained.

The interview next turns to orgasm; this should occur in every case. It is easy to assume that, if erection does not occur or vaginal penetration and intercourse do not occur, that orgasm is moot. Nothing could be farther from the truth. In fact, men do not need erections in order to reach orgasm; with intense stimulation, most men will experience orgasm whether or not they have any erection. Similarly, women do not need lubrication, vaginal penetration, or intercourse to experience orgasm. In fact, it may be more likely that women will reach orgasm with intense stimulation other than intercourse. This section of the interview can be enlightening for both the interviewer and also for the person interviewed, who may think of sexual options for the first time that have previously never been considered.

The final phase of assessment includes questions about resolution and the refractory period. If the sexual activity was satisfying and culminated in orgasm, it is unlikely that problems will be described. If the sexual activity is less successful, and one or both partners do not experience orgasm, resolution phase can be more problematic. The patient with Alzheimer's may become more agitated and uncomfortable, especially if he or she did reach some level of physical arousal that now will take time to dissipate. The non-demented partner may also feel frustrated, physically and emotionally, and this may affect thoughts and feelings over an extended time while resolution of sexual arousal diminishes gradually and with difficulty, rather than in rapid, intense orgasmic release. Thus, sex that leaves either or both partners "hanging" may contribute to sexual and nonsexual dissatisfaction in the relationship.

As must be clear from the discussion above, sexual functioning assessments typically include words and language that people use on very rare occasions, therefore it can be very helpful to practice asking questions about sexuality before entering into a real life assessment.

INTERVENTION FOR SEXUAL CONCERNS

The PLISSIT model (Annon) (19) provides a useful intervention framework that is typically used by sex therapists. The 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 educational 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 professional therapists trained in sexual issues. Health care professionals can use the PLISSIT framework to address a couple's sexual difficulties; some problems can be handled quickly and others will take more time and commitment from both the clients and the health care provider. It is best to include caregivers in these assessments because the dementing illness may make the patient's self report unreliable. Table 2 illustrates use of the PLISSIT model with AD patients and their partners.

With regard to sexual problems discussed in this paper, there are viable suggestions that the health care professional can offer the couple. Erectile dysfunction have been successfully treated with vacuum pumps, injections, and implants. However, these interventions can be frustrating for someone with cognitive impairment. It will be necessary for the partner to assist in the implementation of these interventions. The caregiver may need to assist the patient in other areas of sexual intimacy, such as cases where the patient has lost some capacity to perform the sequences of lovemaking behaviors. When providing suggestions to a couple, it is useful to ask the couple what kinds of changes they would feel comfortable implementing. Some suggestions such as mutual

Table 2. PLISSIT Model for Use with Alzheimer's Disease Patients and Caregivers

Abbreviation	Level of Information	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 (e.g., 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.

manual stimulation, oral sex, and female superior position may be well received by some couples, but not by all.

The clinician 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 adaptation to changes in sexuality. These couples may benefit from a few counseling sessions where they discuss ways to continue expressing their fondness and affection for one another, e.g., increase hugging, kissing, stroking.

The following example is drawn from a caregiver's own description of some of the changes that had to occur for sexuality to remain a positive part of her life with her husband. These strategies could well inform the work of professionals providing intensive therapy for sexual concerns:

"I can acknowledge that I want lovemaking, despite Julian's Alzheimer's and all the changes in our lives. Then I must do what I need to do to make it happen . . . Julian's not as eager at sixty-two as he was at forty, but he's interested enough. He's still loving and affectionate . . . I have to find those parts of Julian that still turn me on. We can put on a tape and play Baroque music. We can light a candle and caress. I can snuggle into his arms, recalling lustier times. I can remember how much I have loved him and all that he's been in my life. . . . I drove to the pharmacy and bought myself a frozen yoghurt and two more boxes of Replens" (20).

Some caregivers have concerns and difficulty in determining whether or not their spouse consents to sexual activity. Lichtenberg and Strzepek (21) developed a three step model to assess an individual's capacity to consent to sexual intimacy within a nursing home setting. The first two steps of the model are most appropriate for married couples, and they can be used in any setting, not just the nursing home. For example they could be helpful to caregivers who fear that they may be taking advantage of their spouse. Step one evaluates the patient's awareness of the relationship, i.e., 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?

Step three assesses the patient's awareness of potential risks, and is especially relevant for patients in a nursing home setting. Does the patient realize that this relationship may be time-limited? Can the patient describe how he or she will react when the relationship ends? Does the patient know what medical problems/risks he or she brings to a sexual encounter? Does the patient know what medical problems/risks his or her partner brings to a sexual encounter? Does the patient engage in any behavior with their partner that could threaten health or safety?

Caregivers concerned about possible incidents of inappropriate sexual behavior can be given information that recent research has found that inappropriate sexual behavior in AD patients is a rare event (7). Discussion of inappropriate sexual behavior versus behavior that is due to forgetfulness (i.e., forgetting to zip trousers) could also be beneficial. Caregivers trying to cope with sexual behavior that is truly inappropriate could benefit from individual counseling that 1) identifies the antecedents of the inappropriate behavior, and 2) provides the caregiver with interventions/coping tools that will decrease the behavior.

SUMMARY AND CONCLUSION

Sexuality and the capacity to experience sexual pleasure are lifetime attributes. Forming an integral part of our identity and concept of self, sexuality provides a sense of pleasure, closeness, and comfort. Dementing illnesses can cause changes in sexual functioning that can have detrimental effects on the couple and their quality of life if left untreated. Although several models of intervention are available, few health care professionals directly address the subject. Cultural taboos, personal beliefs, and inadequate professional training contribute to the lack of existing help.

It is not necessary for health care professionals to become sex therapists or have extensive training in sex therapy in order to address the issues of sexuality in older adults. Simple questions can be added during a routine assessment. The physician or nurse can inform the couple that changes in sexuality can accompany the progression of dementing illness and then ask the couple, "How has AD affected your intimate relationship?" Including a few questions about sexual functioning during routine assessments will permit the couple to raise any difficulties they have in this area. It is common for couples to show relief that a health care professional has broached the subject 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 people. Referral can then be arranged if necessary. Leaders of Alzheimer's support groups can make important contributions by increasing their knowledge about and comfort with discussion of sexual intimacy and Alzheimer's disease.

Providing a safe, private, and supportive environment for the expression of sexuality in a residential care facility is an issue that touches every long-term care setting. Health care professionals can also improve their ability to assess and help with sexual dysfunction and concerns by reading, attending workshops and symposia, or taking a seminar in sexuality and aging. Becoming aware of personal biases and beliefs that impact professional practice is essential. Health

care professionals' willingness to address sexuality issues with older adults can reduce patient and caregiver stress and improve couples' quality of life.

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