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SEXUALITY AND ALZHEIMER'S DISEASE:
IMPACT ON THE SPOUSAL RELATIONSHIP

A Thesis
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by
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CHAPTER 1

Introduction

Purpose of the Study

Alzheimer's Disease is the most frequent cause of irreversible dementia in this country. It has been estimated that 1.2 million to 4 million Americans, age forty and older, may be affected by this disease. At this time, there is no known cure or medical treatment available for the disease. A definitive diagnosis can only be established after death, by an autopsy. The major behavioral symptoms are gradual deterioration of memory, intellect, and self-care ability leading to progressive dependence and eventual death.[1]

Research has shown that caregiving tasks tend to be taken over predominantly by women. Family caregivers undergo significant role changes and increased responsibility, including taking over the tasks or functions previously performed by the person with Alzheimer's Disease. Eventually they even provide care for such basic needs as bathing, dressing, bowel care, and feeding.

The caregiving spouse's experience with a person who has Alzheimer's Disease has been defined by some as the "ongoing funeral, as the caregiver witnesses the ...progressive and agonizingly slow death of the human side of existence, for its ultimate residue is no longer recognizable as a person".[2] "The caregiver ...of the demented patient grieves for the loss of the person they knew. But their mourning is incomplete".[3] Lezak reflects on the caregiver's dilemma when she states:

> The spouse cannot mourn decently. Although [the caregiver has] lost [his/her] mate as surely and permanently as if by death, since the familiar body remains, society neither recognizes the spouse's grief, nor provides the support and comfort that surrounds those bereaved by death.[4]

The purpose of this study was to explore one aspect of the unique relationship between the caregiver/spouse and her Alzheimer afflicted husband, namely, their sexual relationship. The sexual relationship of the couple may be affected by both the functional and the psychological changes in the spouse with Alzheimer's Disease. Sexual problems which occur include impotence, increase or decrease in sexual drive, or affective changes.

This study focused on the female caregiver's perspective of the couple's sexual relationship and was guided by the following questions:

1. What impact does Alzheimer's Disease have on the couple's sexual behaviors?
2. Has the couple's sexual functioning changed? If yes, what are the changes?
3. What coping mechanisms are caregivers using to contend with these changes in sexual functioning?

Rationale

Caregivers of persons with Alzheimer's Disease are often overwhelmed with the stresses of caring for their spouse. One way of reducing some of these stresses is to increase pleasurable activities.

Although sexuality may not be a primary concern for caregivers because of the burden of caring for their spouses, it may still be an important aspect of their lives which could help to sustain the marital relationship, even for a short period of time.

When helping professionals work with the caregiver and spouse who are coping with Alzheimer's Disease it is not surprising that the issue of sexuality may be overlooked or seen as negligible. Only in recent years have helping professionals recognized the importance of discussing sexuality during assessment and treatment phases.

Professionals working with these couples need to be knowledgeable of the changes that may take place in the couple's sexual functioning, and the possible impact of these changes on the marital relationship. They will then need to skillfully intervene to help the couple, or the caregiver, cope with the differences in current functioning which may have occurred as a result of the disease.

It is hoped that this study will contribute to the growing body of knowledge about the social impact of Alzheimer's Disease on the family and will assist helping professionals toward developing a holistic approach to the problems of caregivers, specifically in the arena of sexuality.

CHAPTER 2

Review of the Literature

Introduction

A review of the literature indicates that limited data are available on the changes in the sexual functioning of persons with Alzheimer's Disease and the impact of these changes on caregivers. The limited data highlight the importance of this exploratory study and, in general, the need for more research on sexuality and Alzheimer's Disease. However, the literature contains many articles on the medical aspects of the disease and the psychosocial interventions of helping professionals with families and caregivers of Alzheimer's patients.

Alzheimer's Disease

Although some memory loss is normal with aging, research has shown that Alzheimer's Disease is clearly an organic neurological disorder. In fact, Alzheimer's Disease is the most frequent cause of irreversible dementia in adults.

> The cause is unknown as yet, but investigators are studying the possible role of such causes as: immunologic and environmental/toxic factors which may be involved singly or in combination. Investigators are also studying the epidemiology of the disease as well as its natural history. Cure is currently not available.5

Alzheimer's Disease is the fifth leading killer in this country and strikes an estimated 1.2 to 4 million Americans age 40 and older, and in nursing homes, about half of the population has Alzheimer's Disease.[6] Because there is no cure at this time, treatment centers on managing the behavioral changes that accompany neural deterioration.

The progressive deterioration of a person with Alzheimer's Disease has been described in three major stages. The first stage is forgetfulness, which may last from one to ten years. The patient experiences recent memory loss and may have difficulty remembering names, numbers, and where things are placed. During that stage, families may experience some social disruption, marital conflict, and employment problems.

The confusional stage comes next and is marked by continued deterioration of cognitive functioning. During this stage, both recent and remote memory are affected and the person may have difficulty recognizing names and faces. Abstract thinking gradually declines. Especially noticeable is the decline in self-care ability. It becomes increasingly more difficult for the patient to feed, dress, and toilet himself.

The final stage is referred to as dementia. At this point, the patient may be disoriented, have difficulty recognizing his spouse or other family members, and may even demonstrate psychotic-like symptoms. Incontinence and wandering may become more pronounced. The person eventually becomes non-ambulatory and bedridden, as the brain gradually forms neurofibrillary tangles and senile plaques. Even at this stage, some patients may live on for years.[7]

The effects of Alzheimer's Disease on families and caregivers are devastating. Family members may become depressed, socially isolated, and fatigued. They naturally mourn their own losses in seeing their loved one deteriorate psychologically and physically.[8]

Sexuality and Aging

Physiological Changes

This study focuses on the heterosexual couple but may apply to homosexual couples as well. According to Masters and Johnson, older men (defined as those in the 50 to 70 age group) may experience some measurable physiological changes in their sexual response cycle in the course of normal aging. For older men, the excitement phase may show a slower attainment of erection as compared to when they were younger. The plateau phase usually lasts longer for older men, making it possible for them to maintain sexual stimulation of the partner for a longer period of time. Changes in the orgasmic phase for older men are manifested by a shorter duration, less intensity, and a release of a smaller volume of seminal fluid. Finally, the resolution phase of the older man's sexual response cycle may be longer, up to several hours or days before a return to full erection is possible.[9]

Masters and Johnson also studied the changes in the sexual response cycle of older women (defined as those in the 50 to 70 age group). During the excitement phase, older women may experience a delay in vaginal lubrication when responding to sexual stimulation. In the plateau phase, there is decreased elasticity in the vaginal barrel, but the clitoris continues to function. The orgasmic phase for older women is significantly shortened as compared to younger women. The resolution phase after the orgasmic experience is fairly rapid.[10]

Many sexual functioning problems experienced by older people are due more to social misconceptions and myths, than to actual sexual dysfunction. Masters and Johnson state:

> That phase of human activity most surrounded by misconception, fallacy, and taboo is sexual function. If some concept of the naturalness of sexual functioning in the 50 to 70 year age group can be accepted by the medical and behavioral professions, there will be no reason to confuse symptoms relating to sexual dysfunction with those of the natural, physiologic involution of the aging process.[11]

In addition to psychosocial influences, one must consider the likelihood of chronic disease processes such as diabetes and hypertension as an influence on sexual dysfunction. Although abnormal states, these disease processes commonly have a higher occurrence among the elderly. Many times medications which interfere with and impact on the sexual functioning of older persons are prescribed for their illnesses.

Psychosexual Aspects of Aging

In an article entitled "Touch and Human Sexuality in Later Life," Bernita Steffl points out that:

> Little research has been done regarding the value and meaning of loving touch in the sexuality of older adults, but that does not mean that information is not available. Contrary to popular opinion, older adults are willing and eager to discuss their sexuality.[12]

In discussing sexuality and old age, Powell and Courtice state that:

> When we consider the many sources of depression in older people, it is worth noting that the relationship between sex and depression in the elderly is an inverse one. The more interest an older person has

> in sex and the more opportunity he has to participate as a sexual being, the less depressed he is. Orgasm has the power to confirm and to recreate our reality. Thus enhanced sexual interest and activity can be an antidote to depression.[13]

And, according to Shere Hite, "Sexuality and the capacity to experience sexual pleasure are lifetime attributes."[14]

Cultural attitudes toward sexuality and sexual functioning can affect persons at the core of their concept of self as male or female, a phrase commonly termed gender identity.[15] Elderly couples who have integrated a lifetime of these attitudes and now face the ravages of Alzheimer's Disease, may find themselves in a social dilemma in which their sexual needs are unmet.

Sexuality and Alzheimer's Disease

One of the issues that is addressed in the literature about Alzheimer's Disease is inappropriate sexual behaviors, which are defined as fidgeting with zippers, removing clothing in public places, and masturbating at inappropriate times and places.[16] Demented spouses who are frustrated, confused, and who have difficulty in communicating their needs, may inappropriately express a normal human need for physical touching and intimacy. While these behaviors are often embarrassing to families and caregivers, neither these behaviors nor their impact on the sexual functioning of the spousal system, is included in the foci of this study.

In their book, "The 36-Hour Day", Mace and Rabins note that some people with Alzheimer's Disease may have a diminished or increased sexual drive. They state that people have a lifelong need to be loved and touched, and that sometimes sex remains one of the pleasurable activities a couple can share. However, Mace and Rabins suggest that:

> If a person develops increased sexuality, (sic) remember that, however distressing this is, it is a factor of the brain injury. It is not a factor of personality or a reflection on you or your marriage.[17]

Their statement is based on an implicit assumption and generalization that an increase in the sexual drive of the demented spouse would always be distressing to the healthy spouse. While this assumption may be well-founded for some couples where the wife may recognize an increase in sexual drive as a pathology of the illness, it cannot be generalized to all cases.

Lissa Robins-Kapust presents another perspective of the unique physiological and psychosexual issues associated with Alzheimer's Disease:

> In a marriage, when one partner has dementia, there are alterations in the way love is given and received. But sexuality is not erased from the relationship by the onset of the illness. ...For the healthy spouse sexual needs may remain unchanged, with a continued wish for closeness and affection. However, for the patient, sexual alterations may become integrated into the symptomology of his illness. The emotionally withdrawn patient may lack sexual interest or may be emotionally insensitive to his spouse's need for affection. The agitated patient may make incessant, inappropriate demands. The patient may appear selfish in any sexual encounter, satisfying only his own needs with no concern for his partner.[18]

Powell and Courtice also found that:

> The healthy caregiving spouse, however, frequently finds it difficult to participate sexually when the emotional aspects of the relationship are missing. Many women complain that they are being used as sexual objects by their afflicted spouses, while getting no

> sexual satisfaction themselves. Other women feel that their spouse has so few pleasures that they participate sexually merely to give comfort to their partner.[19]

Because the relationship is so changed by the memory impairment of one spouse, it is difficult for some caregivers to agree to sexual activity.

> Some husbands and wives reject the sexual overtures of a memory-impaired spouse because the total relationship is affected by the illness. Unable to communicate with their spouses, they no longer feel comfortable making love. Also, a caregiver who is totally involved in attending to the Alzheimer's Disease patient's daily needs may be too tired or too depressed to be interested in sex.[20]

Lissa Robins Kapust observed that:

> The physical and emotional alterations consequent to this disease create a ...predicament for the healthy spouse. The healthy spouse ...[often] ... becomes socially isolated, living in social limbo, feeling neither married or single.[21]

Some spouses have considered themselves "married widows and widowers" because of the deterioration of the relationship and the continued life of the memory-impaired spouse.[22]

The spouse of a person with Alzheimer's Disease may find it difficult to seek out and engage others for companionship and/or sexual relations. The healthy spouse may still feel emotionally, morally, and legally bound to the partner. Always present is the sense of responsibility for the care of the demented spouse. The burden of providing care tends to physically and psychologically consume the caregiver, leaving little time or energy to satisfy their own social or sexual needs, even if morally sanctioned.

A New Definition of Sexuality

Some researchers have a broader perspective of sexuality and sexual expression, as they recognize that "Touching is Sex Too."[23] Not all sexual expression needs to end in intercourse. Shere Hite found that touching, hugging, kissing, and massage, are as important in the sexuality of loving couples as in intercourse. For many, intercourse is secondary compared to the pleasures derived from intimate touching.[24] Persons with handicaps or illnesses that inhibit sexual activity may find that this broadened view of sexuality enhances their relationship while providing some form of sexual expression and satisfaction, which may lead to a new closeness for the couple.

Women Caregivers

It is especially difficult for women caregivers to discuss their sexual problems with a doctor. Alex Comfort confirms this omission by stating:

> Medication unquestionably affects sexual response in women as well as in men, but for cultural reasons and because of the greater complexity of female sexual physiology, no serious attempt has been made in past literature to document any but the grossest changes. It is virtually certain that drugs are prescribed which interfere with the pattern of orgasm in women, but male oriented clinicians have not documented them, and patients have not reported them.[25]

Not only are women caregivers overwhelmed with the duties of caring for their spouses, but they must also set aside many of their own needs and desires in the process. During this time, they seldom have anyone to confide in about their sexual concerns. In many cases, not even their doctors are available for discussing sexual matters. One might speculate as to some of the reasons for this omission: 1) most physicians are men; 2) most physicians have not been educated about sexuality; and 3) physicians commonly hesitate to discuss sex with women their mother's age.

Conclusion

Research has shown that in healthy people, sexual activity and capacity for intercourse and orgasm are lifelong. Although normal aging may slow responses there has been no documentation of a decreased interest in sex in older women. Many of the changes that take place after menopause are probably attitudinal and grounded in the social image of the older woman, rather than in actual physiological changes. For many older women today, it is common to see an increased interest in sexuality, rather than a loss or decrease of interest. The greatest inhibitor to sexual expression for older women is the lack of a socially acceptable partner.

Sexuality and sexual expression are crucial to the integrity of the personality from infancy through old age. Alzheimer's Disease brings about changes in personality, perception of the world, and awareness of self and others. These changes may be devastating to both the marital relationship and the healthy spouse. When the husband has Alzheimer's Disease, the wife does not necessarily become asexual. Identifying the changes that take place in the sexual functioning of the couple, as well as how the wife copes with the changes, are the foci of this study.

CHAPTER 3

Methodology

Research Design

Because the area of sexuality and Alzheimer's Disease has not been studied previously, this exploratory study was designed to gather sufficient data from spousal caregivers of Alzheimer's patients to:

1) determine whether the disease has any impact on the couple's sexual behavior;

2) define that impact and identify caregivers' reactions and responses;

3) identify the caregivers' major concerns about the impact of the disease on spousal sexual behavior;

4) determine whether further research with a larger random sample is indicated;

5) determine whether current social work interventions with caregivers indicate that social workers address the issue of sexuality and Alzheimer's Disease;

6) raise the consciousness of social workers and other helping professionals with respect to the possible need for interventions dealing with the impact of Alzheimer's Disease on the couple's sexual relationship.

This study was planned and implemented within the organizational context of the Menlo Park Division of the Veterans Administration Medical Center, Palo Alto, California. Within this context, the study was viewed as a part of an ongoing quality assurance program and was reviewed by the Social Work Service Research Committee to insure compliance with the Protection of Human Subjects Committee's guidelines.

Sample

The sample of eleven caregivers selected for this study consisted of female, white, middle class, spousal caregivers of Alzheimer's out-patients at the Menlo Park Division of the Veterans Administration Medical Center, Palo Alto, California. Best described as a convenience sample, it included all the Alzheimer's spouses available to the investigator through her employment as a social work intern at this agency. All participants care for their Alzheimer's spouses at home.

The age range of the respondents was fifty-six to eighty-three years, and the age range of their partners was sixty-two to eighty-seven years. These women had been cargivers for one to ten years.

Some of the respondents were chosen from participants of the Elder Vets Day Respite program and from other associated gerontology programs in the medical center. Four of the participants were known to the investigator through her work at the Elder Vets Day Respite program prior to the interview, but the remaining seven were not.

Because of the nature of the sample, conclusions from this study cannot be generalized to the larger population of Alzheimer's caregivers until further studies can be undertaken with a more representive sample.

Measurement

The instrument used in this study was an interview schedule. It was chosen over a questionnaire because of the delicate nature of the subject matter as well as the need to probe for greater depth of information. There was also the need to establish a relationship with the participant prior to, and during, the interview. The investigator believed that the subject was best discussed in a face to face interview, enabling follow-up on verbal and non-verbal cues.

It is important to mention here that the interview schedule used in this study was a new instrument and was being tested for the first time. A larger random sample of respondents would be needed to determine the validity and reliability of the instrument. Additions to the instrument were made after the initial two inverviews. (See appendix A)

The exploratory nature of the study demanded an open-ended questioning approach. The interview schedule was arranged in such a way as to allow respondents to define key terms in the beginning of the interview in their own words, thereby reflecting their own ideas and experiences and providing a semantic map of the connotations of each term.

Procedure

Possible participants were approached by telephone contact or in person when bringing their husbands to the program, to determine their willingness to participate. They were given a brief explanation of the purpose and content of the study and the time commitment expected of them, should they decide to participate. Of the fourteen possible participants who were approached, eleven agreed to participate. In most cases the interview took place within a week after the initial contact.

Interview Procedures

Respondents who agreed to participate were given a map and directions to a small comfortable office in the Administrative Core building at the Menlo Park Division of the Veterans Administration Medical Center, Palo Alto, California. When they arrived they were greeted by the investigator and wree then asked to review, and decide if they wished to sign, a concent form which met with regulations of the VA concerning subjects' rights when participating in a study. (See appendix B) All eleven respondents chose to sign the consent form.

The initial part of the one hour interview dealt with demographic data to help put the respondent at ease. The topics of sexuality and intimacy were gradually introduced after rapport had been established. Each respondent was asked to define the terms "love", "sexual activity", "sexuality", and "sex". Questions concerning the respondent's sexual relationship with her husband began with a description of their relationship before the onset of symptoms.

The next set of questions covered the participant's current sexual relationship with her husband. Finally, the end of the interview included a needs assessment for the VA regarding caregiver support services and a review of how the interview was experienced by the participant.

Special Considerations

Because of the possibility of participants becoming very distressed during the interview, it was necessary to be prepared to discontinue the interview until a later date or to allow the participant to drop out of the study altogether. Thus, if it became apparent that any caregiver was in need of counseling as a result of feelings triggered by this interview, or about other concurrent issues, the investigator was able to set up an appointment or make a referral to competent counsellors within the VA Medical Center. In the course of the interviews, it was not necessary to discontinue or refer any participant.

CHAPTER 4

Results

Demographics and History of the Disease

All eleven of the participants included in the study were women. The study was conducted through the Palo Alto Veteran's Administration Medical Center, Menlo Park Division. All of the women were wives of veterans who were participants in programs at this VA. The age range of the respondents was fifty-six to eighty-three, with a median of sixty-seven. The age range for their spouses was sixty-two to eighty-seven, with a median of seventy-one. All of the respondents had been married for many years, with the shortest marriage being thirty-five years and the longest fifty-nine years.

In order to assess the scope of the respondents' experience with Alzheimer's Disease, it was necessary to determine how long they had been coping with the changes in their husbands' behaviors and what kind of caregiving functions they performed for their husbands. Most respondents knew that their husbands had had Alzheimer's Disease for five years or more. Many stated that they suspected "something was wrong" for many years before the diagnosis. For the family, those early years were a time of covering up and denying that there actually was a problem.

All of the respondents were their husbands' primary caregivers, and they performed a wide range of caregiving functions from food preparation and feeding to bowel and bladder care. Almost all the respondents agreed that their spouses required supervision of all activities in their lives. This fact is significant in helping to understand the responses of these women later in the interview schedule. Their responses need to be analyzed with consideration of the current level of stress, loss, and substantial burden they bear in caring for the spouse with Alzheimer's Disease.

Pre-diagnosis Sexual Activity

This segment of the interview schedule was designed to assess how the respondents defined sexual activity and related emotions. It was also necessary to collect some pre-diagnosis history of their sexual activity to compare with their current frequency of sexual activity and degree of satisfaction.

Most of the women reported having no difficulty in discussing sexual issues. The fact that the majority of respondents felt comfortable discussing sexual issues is significant because of the myths surrounding older women and sexuality; namely, that they are not only disinterested in sex, but that they do not feel comfortable discussing the topic. Most of the respondents were willing and even eager to talk to someone about this aspect of their lives.

Respondents were asked if they or their husbands had any physical problems or illnesses that may have interfered with their sexual activity before the onset of the disease. All of the respondents reported having had no physical problems or illness requiring medication before onset. Only three of the husbands had physical problems that interfered with their sexual activity. One had been an alcoholic who went through detoxification some eighteen years ago. His wife felt that the medications he took since his detox had some effect on the frequency and quality of their sexual activity. Another husband had had prostate surgery in 1970 and, to his wife's distress, had not experienced an erection since. He was not on any medication. Of the eleven participants in this study this was the only case where the couple had had a long history of sexual dysfunction in their marriage before the onset of Alzheimer's Disease.

The following segment of the interview schedule was designed to assess the level of sexual intimacy shared by the couple prior to the diagnosis of Alzheimer's Disease. All respondents reported that they had slept in the same room with their husbands before the diagnosis. Only three women reported sleeping in separate beds. Reasons respondents gave for separate beds were that their husbands were noisy, restless sleepers. One of these was the couple with pre-onset sexual dysfunction.

When asked how often they engaged in sexual activity, as self-defined by the participants, with their husbands before the onset of Alzheimer's Disease the respondents reported a fairly high frequency of sexual activity. Table one summarizes these findings.

Table 1

Frequency of Sexual Activity, Pre-diagnosis

Frequency	Number of Respondents
two to three times a week	7
once a week	2
once a month	1
none at all	1

Although it is not certain that all the respondents were reporting on the basis of frequency of intercourse, their responses supported the assumption that they were.

In addition to actual sexual activity, most respondents reported a high frequency of kissing, touching, and hugging in their relationship with their husbands before the onset of Alzheimer's Disease.

Hypothesizing that after the onset of Alzheimer's Disease symptoms respondents may have discouraged sexual advances from their husbands, the interview schedule included questions concerning their pre-diagnosis behavior regarding this subject. Seven respondents reported that they had discouraged their husbands' sexual advances previously and four felt that they had not. The major reason reported by the seven who had was that they were too tired or not in the mood. It is important to keep in mind that these were reported as occasional occurrences.

When asked who had usually initiated sexual activity, most respondents felt that their husband had. Two women felt that they had sometimes initiated sexual activity, and one woman reported that she usually initiated sexual activity in the marriage. Findings summarized in Table 2 assess the caregivers' satisfaction with their sexual activity before onset.

Table 2

Wives' Satisfaction With Sexual Activity Pre-diagnosis

Rating	Number of Respondents
Completely	4
Somewhat	5
Average	2
Not Very	0
Not at All	0

These responses reveal that this group of women had a high level of satisfaction with the frequency of sexual activity in their marital relationship before the onset of Alzheimer's Disease. It is important to point out here that the two respondents who experienced low to no sexual activity were also satisfied, or at least reported that they were satisfied, with that frequency.

When asked if they had a close friend or relative to confide in about sexual concerns, three of the respondents reported that they had, and eight said that they did not. While this finding suggests that they did not have the need for support, it may also suggest the lack of a close friend or relative available for such support.

The final questions in this segment of the interview schedule asked if the respondents felt that they were in love with their husbands prior to the Alzheimer's diagnosis. Most respondents reported that they definitely felt that they were in love with their husbands at that time.

In summary, ten of the respondents reported fairly normal relationships as well as a fairly high frequency of sexual activity with their husbands before the onset of Alzheimer's Disease. Only one respondent reported a dysfunctional sexual relationship prior to her husband's diagnosis. This knowledge base of the history of the sexual relationships may be helpful in assessing any changes that may have come about in their sexual functioning since the onset of Alzheimer's Disease.

Post-diagnosis Sexual Activity

When asked if they currently had any physical problems or illnesses that may interfere with their sexual activity with their husbands, four women answered "yes," and seven said "no," Of the four women who reported physical problems: one had had a mastectomy four years ago; one had experienced some decreased vaginal lubrication; one now has diabetes not requiring medication; and one had had a hysterectomy in 1985, has developed diabetes requiring insulin management, and has had radiation treatments.

These results show a significant increase in the physical problems of these women compared to their health status prior to their husbands' diagnosis. It is difficult to make assumptions about the causes of these changes but some may be due to the stresses involved in caring for a demented spouse. Of these changes, only the changes in vaginal lubrication can be attributed to the normal aging process. Other changes are pathological.

As cited earlier, before diagnosis three of the husbands had had physical problems. In discussing the health status of their husbands after diagnosis, caregivers reported little change: one has hypertension regulated with medication; one has impotency, defined as not being able to achieve an erection; one has diabetes, not requiring medication; and one has emphysema, asthma, and ulcers and was undergoing treatments with radiation and medications.

When asked if they currently slept in the same room with their husbands since the onset of Alzheimer's Disease, eight reported that they did and three reported that they slept in separate rooms. Of the three who no longer slept in the same room since the onset of Alzheimer's Disease, these women reported that it was "just more comfortable that way". Their major reasons for not sleeping together were "he's a noisy sleeper" or "he just gets up too often." These results may be contrasted to the fact that all respondents reported sleeping in the same room with their husbands before the diagnosis.

When asked if they still slept in the same bed, six reported that they still do, and five reported that they now sleep in separate beds. These are their reasons for the change:

"I need my rest, too."

"He moves too much."

"He's a restless sleeper."

"He snores too much."

In the pre-diagnosis section, only three reported sleeping in separate beds. This increase may be related to a desire to avoid physical contact with their husbands. Reasons for this inference become clearer later in this chapter.

When asked about the frequency of sexual activity these women shared with their husbands since the onset of Alzheimer's Disease, eight women reported no sexual activity at all in their current relationship with their husbands. In reporting this figure, it is important to keep in mind that of the eight, one couple was sexually dysfunctional prior to the Alzheimer's diagnosis. Listed below is the frequency of sexual activity of these couples after onset of Alzheimer's Disease

Table 3

Frequency of Sexual Activity, Post-diagnosis

Frequency	Number of Respondents
two or three times a month	1
less than once a month	2
no sexual activity	8

When compared to the fairly high frequency of sexual activity prior to the diagnosis of Alzheimer's Disease, these couples showed a significant decline in the frequency of sexual activity post-diagnosis.

In addition to intercourse, most respondents reported an average amount of kissing, touching, and hugging with little change in the frequency of these activities after the onset of Alzheimer's Disease. Continuing these activities may be one way that these women are able to maintain some level of intimacy in their lives.

When asked if they discouraged their husbands' sexual advances, only four said "yes" and seven stated that they did not. Of the seven who stated that they do not discourage their husbands' sexual advances, the reason given was that he does not make sexual advances anymore. In four cases women reported that their husbands still occasionally try to initiate sexual activity, but that they usually discourage them. These women who said that they do discourage sexual advances from their husbands stated that their reason for doing so is that "he is no longer the same person." Most reported that they feel that the relationship is so altered by Alzheimer's Disease that they can no longer enjoy sexual activity with their husbands. All eleven of the respondents reported that they themselves no longer make any sexual advances toward their husbands. These findings are summarized in Table 4.

Table 4

Wives' Satisfaction with Sexual Activity Post-diagnosis

Rating	Number of Respondents
Completely	6
Somewhat	2
Average	2
Not Very	1
Not at All	0

Once again, even with a significant decline in the frequency of sexual activity, these women reported a fairly high degree of satisfaction. There may be several explanations for this finding, ranging from relief of not having sex as part of their lives anymore, to disgust at having sex with a demented person. Some women felt that it would be more like incest because their husbands are more like children now. Another speculation could be denial that their sexuality is an important part of their lives. They could also be overwhelmed and exhausted by all their caregiving responsibilities and may see sexual activity as a low priority need at this point.

When asked if they had a close friend or relative to confide in about sexual concerns after diagnosis, four women answered "yes," and seven said "no." Most women felt that they did not need anyone to confide in about sexual concerns at this time. However, those who answered "yes," felt that it was helpful to have a confidant.

The final questions in this segment of the interview schedule asked if the respondents felt that they were still in love with their husbands. Most respondents felt that they were still in love before the onset of Alzheimer's Disease. Since the onset of the disease, their perception of the love relationship has changed significantly. Their verbatim responses are listed below:

"I don't think so, not in the same sense."

"He is with me, sometimes I'm not."

"Yes, but it's a different kind of love."

"Yes, in a different way."

"I still love him dearly. We're not in love."

"He values me and I'm devoted to him."

"Yes, as much as possible."

"Yes."

"He loves me and I love him. It makes me cry to say it."

"I don't think so, not for me."

"I don't know. He thinks I'm his mother."

Nearly all of these responses reflect a significant change in the relationship. Some sense of loss is apparent, as well as a change to a maternal kind of love, different from the love relationship they shared before the onset of Alzheimer's Disease.

Current Status and Coping Strategies

Questions in this segment of the interview schedule explored changes in the physical and emotional character of the relationship since the onset of Alzheimer's Disease. When asked if they missed the sexual relationship as it used to be, nine women said "yes," and two said "no." One of the two had a sexually dysfunctional marriage prior to the onset of the disease. Most women reported that they did miss the sexual relationship as it used to be. To impress upon the reader the devastation and the sense of loss experienced by these women, some of their responses have been listed below:

"I miss my entire life as it used to be."

"I miss by beau, my date, my companion, my best friend, and most of all, his sense of humor."

"I miss the physical closeness."

"I miss being together, closeness."

"I miss actual physical contact."

"I miss holding and hugging."

"I miss affection."

"I miss sharing and talking in bed."

These statements reflect the loss of emotional and physical intimacy experienced by these caregivers. Five of these women reported that they still have sexual needs or desires that they feel are unmet. Of these five women, three women stated that they do nothing to satisfy their physical need for sex. One woman reported that she does physical activity, like yardwork, as a release. And finally, one woman reported that she masturbates occasionally to relieve sexual tension.

Six of the women felt that not having intercourse is no longer a problem for them. They have tried to replace the sexual losses with other pleasurable activities in their lives. These activities include walking, attending movies, joining clubs, eating out, and spending time with family and friends. Caregivers are often exhausted from the caregiving functions in their lives and may have little energy left for engaging in sexual activity, which generally declines in importance. Loyalty, morality, and role confusion may also interfere with their desires concerning sexual activity.

The next series of questions in the interview schedule concentrated only on the seven caregivers who no longer shared sexual activity with their husbands. When asked when they stopped having intercourse with their husbands, one stopped less than a year ago, four stopped one to five years ago, and two stopped six to ten years ago. In four cases, the decision was initiated by the wife. In one case it was a mutual decision, and three women reported that it was their husbands' decision to stop.

When asked what they felt was the major reason for stopping the sexual relationship, these women reported that it was mostly due to the husband's inability to remember how to have intercourse or his lack of interest. One woman reported that his increase in sexual drive was more demanding than she could handle.

For those who had stopped having sex with their husbands, the feelings of the respondents ranged from acceptance to relief. Those who experienced only a decrease in their sexual activity felt depressed, sad, and regretful.

Most of the respondents felt that not having sex had little effect on their relationship. It is possible that these women are denying some of the changes that have taken place in their relationships. It is also possible that the relationship has been so altered by the disease that they find relief in not having to confront their sexuality. Important to consider here again is the hierarchy of needs of these women. Caregivers need rest and time off from their duties away from their husbands. Because they are so burdened and because of the added stresses involved in caring for a spouse with Alzheimer's Disease, caregivers may have little physiological or emotional reserve for considering their own needs for intimacy.

VA Needs Assessment

The final segment of the interview schedule included a needs assessment to determine the efficacy of caregiver support services for this VA Medical Center which acknowledges a clinical concern for caregivers. These women attend caregiver support groups and use respite services for their husbands at the Adult Day Respite program within this agency.

When asked if they had sought help with sexual concerns, all eleven respondents said that they had not. One felt that she had a natural reluctance to discuss sexual issues. Ten said that they did not need help because it was not a concern to them. As reported in Table 5, most of these women were interested in clinical services currently offered at this VA. Some were, in fact, already using these services.

Table 5

Caregiver Service Needs

Service	Rating
Couple Counseling	0
Individual Counseling	6
Group Counseling	8
Support Groups	10
Educational Materials	9

Even though these women had not previously sought help with sexual concerns, they still felt that there was a substantial need in their lives for support groups and counseling services where the topic of sexuality could be discussed. All eleven of the respondents felt that this interview about sexuality was comfortable for them, indicating that older women can be comfortable discussing sexual issues.

Finally, the respondents were asked if the interview raised any specific concerns for them. Two answered "yes," and nine answered "no." Of the two women for whom the interview raised concerns, one stated that "I wonder if I should think about sexual activity." The second said "I'd like to know how other women handle these problems."

CHAPTER 5

Conclusions and Recommendations

Conclusions

The purpose of this study was to identify the changes that take place in the sexual relationship between a husband and wife when the husband has Alzheimer's Disease. The focus was on the caregiver's perspective, and in this case, the caregivers were all wives. An attempt was made to identify caregiver coping mechanisms and needs in terms of intimacy and social support.

It appears from the results of this study that the marital relationship experiences radical changes in regard to sexual functioning when one partner develops Alzheimer's Disease. The majority of cases showed a significant decline in the frequency of sexual activity after the onset of Alzheimer's Disease when compared to the sexual relationship before the onset of the disease. The major reasons for this decline, according to the caregivers, is that the husband can no longer perform, or that he is no longer interested in sex. Another reason for the cessation of the sexual relationship is that the total relationship is so altered by Alzheimer's Disease that the demented person may see his wife as his mother, and the wife, experiencing role confusion, may begin to relate to her husband as if he were a child. Under these conditions most women find it extremely difficult to agree to sex.

Another aspect of the changing relationship is the burden of care and increased responsibilities assumed by the caregiver. More important than the need for sexual satisfaction and intimacy in her life, the caregiver needs physical rest, respite from her caregiving tasks, and some social contacts outside of her deteriorating relationship with her husband.

One of the ways caregivers cope with the changes in their lives is through the defense mechanism of denial. During the early stages of the disease they try to cover up small mistakes and inadequacies of the demented person. Later, they go to great lengths to keep up a social image for as long as possible. They dress their husbands neatly and try to maintain all the appearances of a normal couple. They seem to be trying to hold the marriage together on the outside, while watching it crumble on the inside. Even when there was a marked decline in the frequency of sexual activity in the marriage, caregivers still reported a high degree of satisfaction despite that decline.

If the need for sex is lifelong, these findings raise questions which could generate further research. Why are these caregivers reporting that sex is not very important to them? How much are these women denying? Does the need for sex take on dimensions other than intercourse? How great is their need for a confidant?

Caregivers have the need to grieve the slow death of their spouse and the denial system may interfere with that grieving process. As long as they keep up the social image of the normal couple and deny their own needs for rest, respite, sexuality, and intimacy, they may continue to cope in ways that may be detrimental to their own physical and psychological well-being because of their investment in the caregiver role.

One of the ways caregivers in this study found help was through the caregiver support groups available to them through this VA. At group meetings caregivers find solace in knowing that others have the same problems and they learn to share ways of coping without feeling stigmatized. Support groups offer a forum for grieving losses as well as learning what may be expected with future changes in the demented person's behavior. For many caregivers, these groups may be their only social life outside of their caregiving responsibilities. For those without understanding families and friends, group membership may offer their only psychosocial support.

Recommendations

It is important for social workers and other helping professionals to discuss sexuality during initial assessment and treatment phases of contact with couples where one spouse has been diagnosed with Alzheimer's Disease. In recent years the holistic approach of multidisciplinary teams has made it clear that clients and patients are complex, and that the best treatment plan is one that includes an assessment of all areas in that person's life.

Alzheimer's Disease changes every aspect of the person's reality. These changes affect family life, employment, and especially the marital relationship. Caregivers grieve as they see their loved ones deteriorating. Along with grief, they may experience anger, frustration, and guilt.

The role of the social worker in dealing with couples where one spouse has Alzheimer's Disease may be complex. The social worker needs to be a psychosocial choreographer, helping caregivers and families to take the necessary steps at the proper time. It is important for helping professinals to understand the changes that take place in normal sexuality and aging as well as the changes that may be expected in the relationship as a result of Alzheimer's Disease.

Annon's PLISSIT model is suggested here as a means of dealing with the sexual aspects of the couples relationship. P-LI-SS-IT is an acronym and a mnemonic device utilized by some professionals as a means of identifying specific sexual problems. Although it is a behavioral approach, other intervention models, such as the psychoanalytic model, may also be applicable. The PLISSIT model has been recommended because of its versatility and applicability to a variety of situations and age groups.

P= Permission: Clients need a non-judgemental sounding board where they are allowed to discuss sexual issues. This level may act as a preventive measure, letting the client know that they are normal and that it is all right to bring up the subject of sex here.

LI= Limited Information: This is usually given along with permission, and generally provides information relevant to the client's concerns. In the case of a couple with Alzheimer's Disease, it may be enough for a caregiver to learn that the patient's sexual behaviors are a result of neural changes and that her response may be associated with normal grief.

SS= Specific Suggestions: Generally, under normal conditions, specific suggestions would require a sexual problem history and behavioral homework assignments. In the case of a caregiver dealing with a demented spouse, specific suggestions may be offered which could help her to find ways of satisfying her own sexual needs or those of her demented spouse.

IT= Intensive Therapy: This stage of intervention requires an extensive assessment of the client's problem and may be long-term therapy. For caregivers who still feel a strong need for sexual satisfaction, a referral to a qualified sex therapist may be helpful.[26]

The PLISSIT model offers the social worker a guide for assessing the level of intervention required for each individual case. If caregivers are given permission to discuss sexual issues from the initial assessment, they will then understand that sexuality is an acceptable area of discussion.

While this study points out the importance of one to one therapy, the PLISSIT model may also be applied to group work. Support groups have been a successful strategy utilized by professionals as a service to caregivers. It is very likely that support groups will continue to be an important network for caregivers of persons with Alzheimer's Disease. All of the women in this study had participated in caregiver support groups and had found them very helpful. It is important for social workers, other helping professionals, and members of multidisciplinary teams to implement the use of support groups in the treatment plan of the couple when one spouse has been diagnosed with Alzheimer's Disease. Many of the issues raised by caregivers can be discussed in a group setting and some caregivers may develop an additional informal support network outside the actual meeting.

In a relationship where one spouse has Alzheimer's Disease, it may be especially puzzling for social workers and other helping professionals to understand the caregiver's shifting from the spousal to the maternal role. The caregiver herself may experience a great deal of guilt and uncertainty, and will need help in sorting out her feelings, both in group settings and individual counseling.

Many of these women are also using denial as a coping mechanism, a strategy which may interfere with the grieving process. The generational impact and the norms for sexuality and relationships that many of these women hold may influence the strong denial of their sexuality more than what younger generations of caregivers would experience. Additional studies with a younger cohort of caregivers would be required to test this hypothesis.

The multidisciplinary team plays an important role in the management of cases when one spouse has Alzheimer's Disease. As members of these teams, social workers and other helping professionals need to establish an atmosphere in which all aspects of the clients' lives can be discussed, including sexuality. The subject of sexuality does not belong to any particular discipline. According to Toni Ayers, R.N., Ed.D., not everyone on a multidisciplinary team, even within the same discipline, is skillful and comfortable in working with sexual issues. She suggests that team members choose someone who has knowledge, expertise, and comfort in sexual matters. This team member can also act as a role model to teach and desensitize other members of the team about this sensitive and important area of the human relationships.[27]

In conclusion, social workers and other helping professionals working with couples with Alzheimer's Disease need to be knowledgeable of the changes that may be expected in the patient's behavior and its impact on the couple's relationship. Although caregivers are faced with many new demands as a result of the disease, it is important for them to know that their sexual needs and desires are valid concerns. Continuing to release tension through intercourse or masturbation may be a healthy way for caregivers to cope with many of the other changes in their lives. Other forms of sexual pleasure may include watching erotic films, reading romantic or sexually explicit books and magazines, and even dancing. Some older people have found that cuddling pets and children satisfies some needs for loving touch and intimacy. For both caregivers and their demented spouses, the need for loving and touching does not end with the onset of Alzheimer's Disease.

Notes

Chapter 1

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21. Kapust, ibid., p. 84.

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25. Comfort, ibid.

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APPENDIX

Appendix A

INTERVIEW SCHEDULE

I'd like you to please answer the following questions as honestly and completely as you can. Take as much time as you need. If you feel uncomfortable about any question you may refrain from answering it.

1. a) How old are you?
   b) How old is your husband?

2. How long have you been married?

3. How long have you known that your husband has Alzheimer's Disease?

4. Are you his primary caregiver?

   a) If no, who is?
   b) What kind of caregiving functions do you perform?

5. Lots of times we feel uncomfortable discussing sexual issues.

   a) Is this something you find easy or difficult?
   b) What can I do to make you feel more comfortable?

6. Sometimes these words mean different things to different people. Would you please tell me what the following words mean to you?

   a) love
   b) sexual activity
   c) sexuality
   d) sex

Now I'd like to ask you some questions about what your relationship with your husband was like before he was diagnosed with Alzheimer's Disease.

7. Did you have any physical problems or illnesses that may have interfered with your sexual activity?

    a) If yes, please describe.
    b) Were you on any medications for these or undergoing any medical treatment?

8. Did your husband have any physical problems or illnesses that may have interfered with your sexual activity?

    a) If yes, please describe.
    b) Was your husband on any medications for these or undergoing any medical treatment?

9. Did you and your husband sleep in the same room before he was diagnosed with Alzheimer's Disease?

    If no, could you tell me a little about that?

10. Did you and your husband sleep in the same bed?

    If no, what were your reasons for not sleeping together?

11. a) About how often did you engage in sexual activity with your husband before he was diagnosed with Alzheimer's Disease?

    b) Did you engage in other forms of physical contact such as:

Kissing	How often?	
Touching	How often?	What kind of touching?
Hugging	How often?	
Other	How often?	

12. Did you ever discourage sexual advances from your husband?

    a) If yes, why?
    b) How?
    c) How did he react?

13. Did your husband ever discourage your sexual advances?

    a) If yes, why do you think he did?
    b) How did he do it?
    c) How did you react?

14. Who usually initiated sexual activity, you or your husband?

15. Overall, how satisfied were you with the level of sexual activity you shared with your husband at that time?

Completely Somewhat Average Not Very Not At All

16. Did you have a close friend or relative in whom you could confide about sexual concerns?

    If yes, were they helpful?

17. Did you feel that you and your husband were in love then?

Now I'd like to shift a little and talk about what your relationship has been like since your husband was diagnosed with Alzheimer's Disease.

18. Do you have any physical problems or illnesses that may interfere with your sexual activity?

    a) If yes, please describe.
    b) Are you on any medications for these or undergoing any medical treatment?

19. Does your husband have any physical problems or illnesses that may interfere with your sexual activity?

    a) If yes, please describe.
    b) Is your husband on any medications for these or undergoing any medical treatment?

20. Do you and your husband currently sleep in the same room?

    If no, could you tell me a little about that?

21. Do you and your husband currently sleep in the same bed?

    If no, what are your reasons for not sleeping together?

22. a) About how often do you currently engage in sexual activity with your husband?

    b) Do you engage in other forms of physical contact such as:

Kissing	How often?
Touching	How often? What kind of touch?
Hugging	How often?
Other	How often?

23. Do you ever discourage sexual advances from your husband?

    a) If yes, why?
    b) How?
    c) How does he react?

24. Does your husband ever discourage your sexual advances?

    a) If yes, why do you think he does?
    b) How does he do it?
    c) How do you react?

25. Who usually initiates sexual activity, you or your husband?

26. Overall, how satisfied are you with the level of sexual activity you share with your husband at this time?

    Completely Somewhat Average Not Very Not At All

27. Do you have a close friend or relative in whom you can confide about sexual concerns?

    If yes, are they helpful?

28. Do you feel that you and your husband are still in love?

29. Do you miss the sexual relationship as it used to be?

    If yes, what is it that you miss?

30. Have you tried to replace some of the sexual losses with other pleasurable activities?

    If yes, please explain.

31. Do you still have sexual needs or desires that you feel are unmet?

32. If yes, how do you satisfy them?

If couple is no longer sharing sexual activity:

33. When did you stop having sex with your husband?

34. Whose decision was it to stop sexual activity?

35. What do you feel is the major reason you and your husband stopped having sex?

36. How do you feel about not having sex with your husband?

37. How has not having sex affected your relationship with your husband?

The following questions are designed to help us meet your needs more completely.

38. Have you sought any help in dealing with your sexual concerns?

Yes What happened?

No Why not?

39. If there were a program available here at the VA, what services would you find helpful?

Couple counseling

Individual counseling

Group counseling

Support group

Educational materials

Other

40. Have you attended any caregiver support groups?

a) Was sexuality ever discussed?
b) If yes, how was that for you?
c) If no, why do you think that is?

41. How was this interview for you?
Has it raised any specific concerns for you?

Appendix B

CONSENT FORM

You are invited to participate in a study about Alzheimer's Disease and sexual functioning. We hope to learn more about the changes, if any, that take place in the sexual relationship of couples when one member has Alzheimer's Disease. You were selected as a possible participant because your husband has Alzheimer's Disease.

If you decide to participate, you will be asked to take part in a one to two hour interview. The interview will include explicit questions about your past and present sexual functioning with your husband. It may be beneficial for you to discuss some of this material with another person, but we cannot, and do not guarantee or promise that you will receive any benefits from this study.

Any information that is obtained in connection with this study, and that can be identified with you will remain confidential and be disclosed only with your permission. If you give us your permission by signing this document, we plan to disclose the nature of the information only, and not your identity.

You will receive no compensation for your participation in this study and you are not expected to contribute to the cost of the study.

Your decision to participate or not to participate in this study will in no way affect you or your husband's eligibility for VA benefits and services to which you are entitled through the Elder Vets Day Respite Program. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions I expect you to ask me. If you have any additional questions later, I will be happy to answer them if you call me at this number: (408) 946-2972.

You will be given a copy of this form to keep.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE HAVING READ THE INFORMATION PROVIDED ABOVE.

DATE: ______________ SIGNATURE (Participant) ______________________

DATE: ______________ SIGNATURE (Investigator) _____________________

Appendix C

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