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Gender differences in sexual behaviors of AD patients and their relationship to spousal caregiver well-being

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Abstract

Objectives—Little is known about gender differences in sexuality among community-dwelling heterosexual couples in which one partner has Alzheimer's disease (AD). Few studies have examined gender differences in specific sexual behaviors or their associations with caregiver well-being. This study evaluated the impact of gender differences on intimacy and sexual satisfaction in marital relationships in which one partner has AD.

Method—Baseline measures were collected from 162 AD patients and their partners enrolled in a multisite study between 2001 and 2009 to evaluate gender differences in measures of intimacy, caregiver well-being, and patient sexual behaviors.

Results—While over 70% of all patients initiated physically intimate activities (i.e. kissing, hugging, and intercourse), most did not initiate intercourse specifically. Female caregivers reported higher levels of stress and depressive symptoms than male caregivers ($p < .01$). Satisfaction with intimacy was significantly associated with fewer stress and depressive symptoms in female caregivers ($r = -.29$, $p < .01$). Caregiver gender, satisfaction with intimacy, and caring for a patient with Mild AD were significant predictors of caregiver depressive symptoms ($ps < .05$).

Conclusion—The majority of couples dealing with AD reported engaging in intimacy, suggesting its importance in the relationship. Female caregivers who reported less sexual satisfaction reported more frequent stress and depressive symptoms. Caregiver gender, satisfaction with intimacy, and the AD patient's level of cognitive functioning significantly contributed to caregiver well-being. Gender-specific therapies to address patient sexual difficulties and caregiver well-being could potentially maintain or improve the marital relationship.

Keywords

dementia; Alzheimer's disease (AD); sexuality; intimacy; gender differences

Introduction

Currently, an estimated 5.3 million Americans have Alzheimer's disease (AD) (Alzheimer's Association, 2010), and this number is expected to grow to 13.2 million by 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). In addition to the impact that this disease has on the patients themselves, caregivers of AD patients may face substantial changes in financial, social, emotional, day-to-day functional, and relationship roles following the onset of the disease. Nearly 40% of patients evaluated for memory problems at the California Alzheimer's Disease Centers between 1985 and July 2007 were cared for by spouses or spouse-equivalents (California Alzheimer's Disease Program, 2007). This highlights the importance of examining the changes that occur in both spousal caregivers as well as in AD patients.

While it is known that there is a decline in sexual intimacy associated with increasing age due to partner loss and declines in health and functionality, older adults who remain in relationships experience frequent non-sexual intimacy (hugging or holding one's partner), sexual activity, and strong emotional and physical satisfaction with their partners (Waite & Das, 2010). Thus, intimacy of all types continues to play an important role in marital relationships as both partners advance in age. Unfortunately, the presence of AD in one partner can significantly affect the quality of a marital relationship (Davies et al., 2010; Mittelman, Zeiss, Davies, & Guy, 2003; Wright, 1991).

A sizeable body of research exists on specific relationship-focused topics including inappropriate sexual behaviors among persons with AD, changes in sexual behavior, erectile dysfunction, and other potentially problematic intimacy issues in this population (Davies, Zeiss, & Tinklenberg, 1992; Derouesne, Guigot, Chermat, Winchester, & Lacomblez, 1996; Zeiss, Davies, & Tinklenberg, 1990; Zeiss, Davies, Wood, & Tinklenberg, 1990). Similarly, issues of patient sexuality such as inappropriate/improper sexual behaviors, the balance between patient sexual needs and patient safety, and ethical concerns surrounding intimacy in group living environments have also been investigated (de Medeiros, Rosenberg, Baker, & Onyike, 2008; Tabak & Shemesh-Kigli, 2006; Zeiss, Davies, & Tinklenberg, 1996). However, there is little information on whether issues of sexuality and intimacy in AD patients and caregivers differ by gender. While previous studies have separately examined gender differences in both AD patients (Lerner, 1999; Ott & Cahn-Weiner, 2001) and caregivers (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Rose, Strauss, Neundorfer, Smyth, & Stuckey, 1997; Thompson et al., 2004), as well as the impact of AD on the marital relationship (Davies et al., 2010; Mittelman et al., 2003; Wright, 1991), few studies have considered gender differences in intimacy and sexuality among married couples prior to nursing home placement of a partner with AD (Derouesne et al., 1996; Dourado, Finamore, Barroso, Santos, & Laks, 2010; Hayes, Boylstein, & Zimmerman, 2009; Simonelli et al., 2008).

Gender differences that could potentially impact intimacy and sexual functioning have been observed in both AD patients and their caregivers. For instance, women with AD were sometimes found to be more reclusive, emotionally labile, and unwilling to accept help than men with AD, while male AD patients may exhibit more psychomotor and vegetative changes (Ott, Tate, Gordon, & Heindel, 1996). A meta-analysis conducted by Vitaliano, Zhang, & Scanlan (2003) found that female caregivers reported significantly more health problems than male caregivers. Results from a subsequent meta-analysis found that female caregivers had lower levels of subjective well-being and higher levels of burden and depression than male caregivers, although only 46% of the studies included focused exclusively on AD caregivers (Pinquart & Sorensen, 2006). Finally, loss of reciprocity in

marital relationships appears to impact overall psychological well-being more for female caregivers than for male caregivers (Hooker et al., 2000).

Among both genders, a variety of factors may contribute to changes in sexuality and intimacy in the marital relationship, including physical limitations, increasing cognitive and functional impairment, behavioral problems, and perceived caregiver burden (Davies et al., 1992; Mittelman et al., 2003; Simonelli et al., 2008). The findings of Simonelli et al. (2008) indicate a significant negative association between caregiver burden and sexual and affective marital satisfaction in caregivers of AD patients, suggesting the importance of intimacy at all levels in caregiver well-being. To our knowledge, only a single study has considered both gender differences in sexual behaviors and how they relate to caregiver well-being (Dourado et al., 2010). Many studies of sexuality and intimacy are qualitative and give separate consideration to either caregiver or patient issues. In this study, we investigate whether there are gender differences in 1) caregiver sexual satisfaction and well-being, and 2) the level of sexual engagement for couples in which one partner has AD. We also examine whether these relationships reflect gender differences in patients' scores on cognitive, functional, neuropsychiatric, and behavioral measures. Finally, we examine associations between sexual behavior/intimacy and spousal caregiver well-being by gender. For the purposes of this study, we extend the term "spousal caregivers" to include caregivers in long-term, committed relationships. Findings may have implications for developing approaches for sustaining intimacy and improving marital relationships.

Methods

Sampling and Procedures

One hundred and sixty-two patients diagnosed with probable or possible AD according to McKhann et al. criteria (1984) were enrolled in the 'Sexuality in Alzheimer's disease' study between 2001 and 2009. McKhann et al. criteria for probable AD require that patients have dementia based on clinical examination and performance on the Mini-Mental State Examination (MMSE) and the Blessed Dementia Scale, deficits in two or more areas of cognition, progressive worsening of memory, no disturbance of consciousness, age of onset between 40 and 90, and an absence of systemic disorders that could account for progressive deficits in memory and cognition (McKhann et al., 1984). Eligible patients had to be community-dwelling, in a committed relationship, and have a partner willing to provide information at baseline and subsequent six-month intervals until patient placement or death. With the exception of the MMSE and patient Geriatric Depression Scale (GDS), described below, all responses were provided by the spousal caregiver.

Cross-sectional data collected at baseline visits were used for the present analysis. All participants in this study were in heterosexual relationships and were recruited either from an AD support group or during a regularly scheduled visit (i.e. diagnostic appointment or routine follow-up) to one of three California Alzheimer's Disease Centers (CADCs): UC Davis Martinez (11.7%), UC Davis Sacramento (11.7%), and Stanford University/VA Palo Alto (76.5%). Recruitment for the study occurred during the scheduled visit or after a support group session. Following an explanation of the protocol and in accordance with University of California at Davis or Stanford University Institutional Review Board, patients and their partners provided informed consent. Baseline instruments were administered by a clinician or a research assistant. Common reasons for declining participation included discomfort discussing intimacy, time limitations, and a preference to participate in research that would have more direct impact on the patient's disease progression (e.g. clinical drug trial).

Measures

Patient Measures of Sexual Intimacy and Relevant Behaviors

A modified version of the Alzheimer's Disease Diagnostic and Treatment Centers (ADDTC) California Dementia Behavior Questionnaire (CDBQ) (Victoroff, Nielson, & Mungas, 1997) was used to evaluate patient behaviors. The questionnaire asks about the presence of behaviors in the last six months and the frequency of behaviors within the last one month. The spousal caregiver completes the form independently. Questions included in the modified CDBQ are provided in Appendix A; items 1-3 are from the original checklist, while items 4-10 were added for this study based on one of the author's experience (HD) and prior work in this area. Frequency of individual CDBQ behaviors (Appendix A, items 1-8 and 10), coded as "0" = "Never", "1" = "Rarely", "2" = "Weekly", "3" = "Daily", "4" = "Constantly" (Victoroff et al., 1997), was used in this analysis.

Measures of Patients' Cognitive and Functional Status

The 30-point Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) and the 17-point Blessed Roth Dementia Rating Scale (BRDRS) (Blessed, Tomlinson, & Roth, 1968) were used to measure cognitive and functional status. Higher scores on the BRDRS and lower scores on the MMSE reflect increased impairment.

Measures of Caregivers' Subjective Well-being

The Caregiver Experience Questionnaire (CEQ) (Victoroff, et al., 1997), a component of the three-part CDBQ, was used to assess caregiver stress and depression in our study. The CEQ contains items derived from Zarit, Reever, and Bach-Pearson (1980) and Zung (1965). Caregivers rate how often they experience emotional distress (including stress, fear, sadness, crying spells, fatigue, and burden) by checking one of four descriptors: "Never", "Rarely", "Quite Frequently", or "Nearly Always". CEQ items were summed to compute a total score ranging from 0-18 (Jeff Victoroff, personal communication).

Caregiver Measures of Sexual Intimacy

Spousal caregiver experience with intimacy was measured by the Sexuality in Alzheimer's Disease Collaborative Study Experience of Intimacy with Partner Scales (EOIPS). The EOIPS is a 3-item face-valid measure. Two items were used in this study. Response choices of both of these items are on a four-point Likert-type scale. The first question asks about "Physical intimacy with my spouse/partner" with the following behavioral anchors: "0" = "We engaged in no physical intimacy at all (kissing, hugging, intercourse)"; "1" = "Our only physical intimacy was occasionally kissing and hugging each other, perhaps once a week"; "2" = "We kissed and hugged about daily, but did not attempt intercourse"; "3" = "We kissed and hugged frequently and attempted intercourse, but could not carry it out"; "4" = "We kissed and hugged and engaged in sexual intercourse to the point of orgasm." The second EOIPS question asks about "My own personal satisfaction with physical intimacy with my partner" with the following response options: "0" = "Very dissatisfied"; "1" = "Dissatisfied"; "2" = "Neutral"; "3" = "Satisfied"; "4" = "Very satisfied". Both EOIPS items were treated as continuous variables in this analysis. In addition, a single item from the CDBQ (Appendix A, item 10) assessing the patient's ability to stay engaged in sexual activity to a satisfying completion for the spousal caregiver was used to assess caregiver satisfaction with intimacy.

Measures Administered to Both Caregiver and Patient

Neuropsychiatric Status—The Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufer et al., 2000) quantifies the presence of behavioral problems for patients and also

measures the distress level of the caregiver for each reported problem behavior. Patient severity total scores range from 0-36 and caregiver distress total scores range from 0-60. Higher scores reflect higher levels of symptom severity and partner distress.

The GDS (Sheikh & Yesavage, 1986), a widely used depression screening scale for the elderly, was the primary tool used to assess both patient and partner mood (Sheikh & Yesavage, 1986). The GDS has high internal consistency and high test-retest reliability. A clinician typically administers the GDS; scores range from 0-15, with a higher score indicating a higher level of depressive mood and a score greater than five indicating clinical depression (Yesavage, 1992).

Demographics on Patients and Caregivers—Demographic data for patients, including years of education, ethnicity, gender, age at study baseline, and age of symptom onset, were collected upon enrollment and verified using the CADC Minimum Uniform Dataset (MUDS). The MUDS is a common data collection tool used by 10 collaborating CADC sites between 1985 and 2009. Data were centrally processed by the Institute for Health and Aging (IHA) at the University of California, San Francisco. Each patient's total number of current medications and co-morbid medical conditions, as determined by a set of 22 co-morbid medical condition items on the MUDS, were also obtained at the baseline visit. Caregiver gender and age at study baseline were collected at the time of study enrollment.

Reasons for Considering Placement in a Nursing Home or Institution—

Caregivers also provided their reasons for placing or considering placement of the patient into a long-term care setting. During subsequent follow-up visits (but not during the initial enrollment visit), caregivers endorsed all of the reasons they have placed or were considering placing the patient (yes/no) from a list of 13 items. For the purposes of this study, we report the last observation available for each patient.

Statistical Analyses—Frequencies for patient and caregiver measures were calculated by gender for comparison purposes. T-tests for normal data and the Wilcoxon Rank Sum test for non-normal data were used to determine whether significant gender differences were present in all continuous variables for both patient and caregiver measures, including demographic measures. Cohen's *d* effect sizes were also computed (Cohen, 1969). Two ADDTC items, patient "believes spouse has been unfaithful" and patient "engages in inappropriate sexual behavior," were excluded due to too few 'yes' responses (< 6). Spearman's rank correlation coefficients were calculated separately for female and male caregivers to identify associations between sexual behavior/intimacy items and the CEQ total score. Hierarchical multiple linear regression was used to examine differences between male and female caregivers on variables that were significant in the Spearman correlations. Regression models were generated with the CEQ total score (caregiver stress and depressive symptoms) as the outcome; predictors for each model were centered and included caregiver gender, a patient sexual/intimate behavior, and the interaction of caregiver gender and the patient behavior.

A post-hoc analysis was conducted to examine the severity of cognitive impairment of the care recipient as an additional predictor in the relationship between the CEQ (caregiver stress and depression) and a significant sexual behavior/intimacy item. The analysis consisted of hierarchical multiple linear regression where we specified the order of entry of all variables in the model. First, severity of cognitive impairment was categorized as mild, moderate, or severe using the following cut-scores on the MMSE (based on tertiles): 24, 19 and < 24, and < 19. Using the procedures described by Cohen & Cohen (1983), the three MMSE categories were accounted for with two dummy coded variables: Mild AD (yes/no)

and Moderate AD (yes/no). In the linear regression model, we entered the main effect for gender (female versus male) (step 1) and our dummy MMSE categories (Mild AD and Moderate AD, versus Severe AD) (step 2). Then we entered interactions between gender and MMSE categories (gender x Mild AD and gender x Moderate AD) (step 3). Finally, we entered caregiver satisfaction with intimacy (step 4). The significance level α was set at .01 for the main analyses to reduce the chance of Type I errors, but set to .05 for the post-hoc hierarchical multiple linear regression analysis.

Results

Baseline Characteristics

Select baseline characteristics are shown in Table 1 (overall and by gender). The average patient and caregiver ages at study entry were 76.80 ($SD = 7.06$) and 73.28 ($SD = 9.0$) years, respectively, and male caregivers were significantly older than female caregivers (77.25, $SD = 8.40$ years vs. 70.67, $SD = 8.50$ years; $p < .0001$). As a whole, the patients were well-educated with an average of 15.35 years of education, although men had significantly more years of education than women (16.00, $SD = 2.88$ vs. 14.40, $SD = 2.58$; $p = .0004$). The mean number of medications the patients were taking was six, and the mean number of comorbid medical conditions was three. The majority of patients were male (59.9%), white non-Hispanic (91.4%), married (99.4%), and living at home with their spouse or spouse-equivalent (98.2%). All patients had a diagnosis of AD (Probable AD: 76.5%; Possible AD: 12.4%; Mixed AD: 11.1%).

Mean total scores on the CEQ were significantly higher for female caregivers than for male caregivers (Females: 8.08, $SD = 3.55$ vs. Males: 5.90, $SD = 3.22$, respectively, $p = .0002$, $ES = -.64$), indicating a greater frequency of self-reported stress and depression among female caregivers. No significant gender differences were found for either caregiver or patient on any of the other cognitive, functional, or neuropsychiatric measures (Table 1).

Reasons for Placement in a Long-Term Care Setting

Of the 162 caregivers, 33% indicated that they have placed or are considering placing the patient in a nursing home. Male and female caregivers reported similar reasons for choosing to place their spouse. The most common reasons were patient functional status (55.6%), cognitive function (51.6%), or problems with incontinence (44.4%). Diminished sexual relationship was ranked 9th among 13 items endorsed, and was reported by 12 (22.2%) of the caregivers who have considered placing their loved one in a nursing home.

Patients: Sexual Intimacy and Relevant Behaviors

No significant differences were found between men and women on any of the ADDTC sexual intimacy and relevant behavior items ($ps > .01$). Mean ADDTC scores in the overall sample and by gender are shown in Table 2 (range = 0-4). The majority of patients were reported to have initiated a physically intimate activity with their spouse within the last month (72.5%), but only 27.5% had initiated intercourse within this same time frame. Most patients were reported to have responded positively to their spouse's initiation of physically intimate activities—from hand-holding to intercourse (82.5%). However, only 36.4% of the patients were reported to respond positively to spouse-initiated intercourse. Inappropriate sexual comments were reported as occurring in 6.3% of the patients. Finally, 27.9% of patients were able to stay engaged in sexual activity without getting distracted or losing arousal. These findings did not differ according to gender. Figure 1 displays the frequency of sexual intimacy and relevant behaviors in the overall sample.

Caregivers: Sexual Intimacy

No significant differences between genders were found on the caregiver sexual intimacy items ($ps > .01$). Less than one-third of all caregivers (30.5%) reported that their spouse was able to stay engaged in sexual activity to satisfying completion for the caregiver (Figure 1). The mean level of physical intimacy, as measured by EOIPS item #1, was 2.11 ($SD = 1.13$) in the whole sample (Females: 1.98, $SD = 1.05$ vs. Males: 2.31, $SD = 1.21$; $ES = .29$), indicating, on average, that both genders kissed and hugged daily but did not attempt intercourse. Both male and female caregivers reported mean levels of satisfaction ranging from “Neutral” to “Satisfied” (2.46, $SD = 0.92$) on EOIPS item #2 (Females: 2.33, $SD = 0.87$ vs. Males: 2.65, $SD = 0.96$; $ES = .35$).

Among female caregivers, higher reported caregiver satisfaction with intimacy (EOIPS item #2) was significantly associated with lower scores on the CEQ, or fewer self-reported symptoms of stress and depression ($r = -.29$, $p = .007$) (Table 3), with this finding strongest in the mild AD MMSE group ($r = -.57$, $p = .0006$). In the male caregiver group, no significant correlations were found between the CEQ total score and the ADDTC and EOIPS items in the overall sample (Table 3) or in the three MMSE groups.

As shown in Table 4, the hierarchical multiple linear regression model (Model 1) revealed that caregiver gender and satisfaction with intimacy (but not their interaction) were significant predictors of caregiver stress and depressive symptoms (CEQ total score), $R^2 = .17$, $p < .0001$. Specifically, female caregivers reported significantly higher stress and depressive symptoms, explaining 8.9% of the variance in the CEQ total score, ($t(148) = 3.21$, $p < .01$). Above and beyond gender, greater caregiver satisfaction with intimacy was associated with fewer stress and depressive symptoms, explaining 8.1% of the variance in the CEQ, ($t(148) = -3.8$, $p < .0001$).

In the post-hoc hierarchical multiple linear regression (Model 2), gender, severity of patient cognitive impairment, interaction between gender and severity of impairment, and satisfaction with intimacy explained 23% of the variance in caregiver depressive symptoms, $R^2 = 0.23$ ($p < .0001$) (Table 4). Female caregivers, ($t(139) = 3.1$, $p < .01$, and caregivers of both genders reporting lower sexual satisfaction, ($t(139) = -3.8$, $p < .01$, had greater depressive symptoms compared with male caregivers or caregivers of both genders reporting higher sexual satisfaction. Caregivers whose loved one had mild AD reported fewer depressive symptoms compared to caregivers of patients with moderate or severe AD, ($t(139) = -2.6$, $p < .05$). Caregiver gender, patient cognitive status, and sexual satisfaction accounted for 10.2%, 4.1%, and 8.0% of the variance in depressive symptoms, respectively. The interactions between gender and cognitive impairment contributed less than 1% of additional variance in depressive symptoms and were not significant ($ps > .05$).

Discussion

Engagement in intimate relations

On average, the AD patients in our study maintained some form of physical intimacy on a weekly basis. The frequency and type of intimate relations that couples engaged in did not significantly differ by patient gender. More than 72% of all patients initiated a physically intimate activity, and an even higher percentage (82.5%) responded positively to spouse-initiated intimate activities. However, these percentages were much lower with regard to sexual intercourse, for both male and female patients. Additionally, more than 72% of all patients were unable to stay engaged in sexual activity due to becoming distracted or losing arousal.

In general, there are many reasons why patients may be less interested in sexual intercourse (e.g. medical conditions, erectile dysfunction, decreased libido, depression, anxiety, diminished energy levels). Lindau et al. (2007) found that the most common cause of sexual inactivity among older adults of both genders was the male partner's physical health. Difficulty with sequencing (a common consequence of Alzheimer's disease) could also be present; patients may be uncomfortable with intercourse because they may not be able to remember the appropriate sequence of steps or the steps that have already been performed.

Contrary to prediction, no gender differences were observed with respect to any of the patient sexual intimacy items. Although we expected males to be less likely to be able to stay engaged in sexual activities without distraction or losing arousal, as the core physical tasks required for engaging in sexual intercourse are more complicated for men than for women, this did not appear to be the case.

Our findings provide support for the idea that couples affected by AD clearly continue to have an interest in and maintain physical intimacy in their relationships, although the activities more often consist of alternatives to intercourse itself. Non-intercourse intimate activities may be preferred over intercourse among both male and female AD patients — in particular, kissing, hugging, cuddling, massaging, and other forms of physical contact. Research has shown that tactile stimulation may reduce stress and behavioral symptoms such as restlessness among AD patients (Woods, Beck, & Sinha, 2009). When the patient is receptive, such activities may help maintain intimacy within the relationship at a level that is comfortable for both members of the dyad. It is important for providers to help couples continue to enjoy intimate relations; this may mean that the dynamic of the sexual/intimate relationship has to evolve to accommodate the patient's cognitive and functional deficits. Providers may need to encourage the caregiver to modify activities so that both members of the dyad can still derive satisfaction from the intimate relationship.

Emotional distress and satisfaction with intimacy

The relationship between emotional well-being and satisfaction with intimacy has been well-established. For example, Rosen and Leblum (1987) discussed previous research which found that depression can cause the inhibition or absence of sexual desire. Butzer and Campbell (2008) found that spouses exhibiting higher levels of anxiety reported lower levels of sexual satisfaction. In the present study, greater satisfaction with intimacy was significantly associated with less emotional distress for female caregivers. Among female caregivers only, higher reported caregiver satisfaction with intimacy was significantly associated with less stress and depression, and this effect was strongest in women caring for those with Mild AD. Indeed, mean total scores on the CEQ were significantly higher for female caregivers than for male caregivers, indicating more self-reported symptoms of stress and depression among women. These results are in agreement with other studies that have found that female caregivers of AD patients have higher levels of burden (Simonelli et al., 2008; Pinquart & Sorensen, 2006). Our finding that female caregivers reporting higher satisfaction with intimacy have reduced levels of stress and depression, is in line with those that have found a significant positive association between satisfaction with intimacy and well-being in women in general (Davison, Bell, LaChina, Holden, & Davis, 2009). Our results also supplement the findings of Dourado et al. (2010), who, in a smaller sample and through semi-structured interviews, reported more feelings of burden related to sexual dissatisfaction in female vs. male caregivers of AD patients.

Caregiver gender and satisfaction with intimacy were associated with caregiver stress and depressive symptoms in roughly equal magnitudes. Caring for a patient with Mild AD also contributed to the variance in caregiver stress and depressive symptoms, although to a lesser degree. Overall, these factors explained 23% of the variance in caregiver depression. Despite

the fact that our findings are similar to those of other studies, our models indicate that additional factors likely contribute to caregiver well-being that we did not consider in our investigation, and may include such factors as the level of caregiver support, financial burden, psychosocial changes, and many others.

On the whole, female caregivers reported more symptoms of emotional distress, and their emotional distress was linked to their satisfaction with intimacy. We speculate that female caregivers may face unique challenges in maintaining satisfactory sexual and intimate relations related to a decreased emotional and physical connection with their partner. Research shows that sexuality in women is strongly tied to a close relationship; that is, an important component of sexual relations is intimacy (Peplau, 2003). As previously mentioned, female caregivers may be more emotionally affected than males by loss of reciprocity throughout the disease progression. Finally, female caregivers also report more symptoms of psychological distress and burden from caregiving routines (Yee & Schulz, 2000). Together, loss of an emotional connection, disappointment, decreased sexual satisfaction, and overwhelming caregiving demands may lead female caregivers to feel disconnected from their partners, resulting in diminished well-being.

Although the purpose of our study was to investigate the impact of sexual behavior items on caregiver well-being, it is important to note that our design did not allow us to assess the directionality of the relationship between these variables, thus it is unclear whether satisfaction with intimacy improves caregiver well-being or whether reduced levels of depression and stress increase the caregiver's ability to engage in or obtain a greater sense of satisfaction with intimacy. Prospective longitudinal investigations are required to determine whether sexual dissatisfaction precedes emotional distress.

Our findings underscore the need to address the underlying cause of the emotional distress and suggest it may be important to teach female caregivers how to enjoy intimate relations despite potential changes in emotional attachment that may occur as the disease progresses. Our results also demonstrate that female caregivers are most vulnerable to experiencing higher levels of distress associated with lower levels of intimacy satisfaction when caring for an AD patient in the early stages of their illness, suggesting that early interventions could be beneficial to this population. While sexual satisfaction was not significantly associated with emotional distress for males, further research should be conducted to ascertain whether underreporting of symptoms may be masking a relationship between the two.

Finally, although male and female caregivers were generally satisfied or neutral with their intimate relations, the majority reported that their spouses were unable to stay engaged in sexual activity to satisfying completion for their caregiver. Distractibility can play a role in completing sexual activities; Alzheimer's patients may forget how to engage in intercourse or immediately forget the activity upon completion, which can cause the spouse to feel rejected or angry (The Rush Alzheimer's Disease Center, 2004). Again, encouragement to pursue pleasurable, functionally-appropriate substitute activities may mitigate the effects of cognitive and functional deficits on sexual activity completion and, as a result, possibly increase sexual satisfaction.

Suggestions for the future

In summary, our results suggest that many couples remain intimate despite one partner having AD. In couples in which there is a newly diagnosed spouse, it may be important to implement interventions aimed at maintaining sexual intimacy as early as possible after a diagnosis is made. The early stages of dementia may represent an opportunity for couples to renegotiate their patterns of intimacy, as new patterns established early in the disease progression appear to be maintained into the later stages (Sherman, 1998). For example, a

structured discussion about each partner's sexual expectations and goals coupled with the development of new relationship rituals including alternatives to intercourse may be beneficial. Therapy to modify specific behaviors that are problematic for the couple could be included. Our results also suggest that interventions in couples where one partner has AD should include sexual intimacy as a component of the treatment. Providers should encourage an open dialogue with patients and caregivers and provide permission to discuss intimate issues openly.

Our findings also suggest that female AD spousal caregivers may face considerable emotional challenges related to decreased satisfaction with intimacy. Individual and family counseling and support groups for this population may be appropriate and effective in reducing depressive symptoms in spousal caregivers of AD patients (Mittelman, Roth, Coon, & Haley, 2004; Chien et al., 2011). Issues facing male caregivers have been poorly examined thus far, as female caregivers remain the focus of most caregiving studies (Baker & Robertson, 2008). Future research should investigate male caregivers in more depth and explore therapeutic approaches in this population. Spousal caregivers may benefit from a focus on alternative ways for couples to achieve intimacy that rely less on prolonged attention from the patient. Taking gender differences into consideration may be beneficial when developing interventions that target caregiver burden and well-being.

Limitations/Conclusion

There are several limitations to our study that are worth noting. Our sample was largely white, non-Hispanic and college-educated. Caregiver depression scores were generally low in our sample; thus, it is possible that replication of this study in a sample of clinically depressed caregivers would yield different results. Participants also consisted of patients and spousal caregivers who agreed to provide information about their marital relationship. As sexuality and intimacy are sensitive topics, our sample likely did not include people who were uncomfortable disclosing details of their personal relationship. This lack of heterogeneity in the sample may limit the generalizability of the findings. In addition, as with any self-report measures, there is the potential for biases to be introduced. The caregiver measures, in particular, rely on caregiver-report of patient sexual behaviors. Finally, our study design was cross-sectional, which prevents us from making conclusions regarding causality.

Although more replication studies are needed, our findings suggest that well-being in female caregivers may be related to intimacy satisfaction levels. Previous research shows that while intimate relationships are affected and modified by AD, AD patients and their partners still have sexual feelings and needs (Davies et al., 1992; Dourado et al., 2010). Improving intimacy and sexuality among AD patients and their caregivers with consideration of potential gender differences in the role of emotional distress is an important avenue for future research, as teaching caregivers to cope with and accept changes in the relationship may enhance relationship quality and decrease caregiver burden. A potential benefit of improved caregiver well-being could be the postponement of patient placement into a long-term care setting (Mittelman, 2003). Delaying placement of an AD patient into a long-term care setting has cost-savings implications for the health care system (Leon, Cheng, & Neumann, 1998; Mittelman, Haley, Clay, & Roth, 2006), which has become increasingly burdened by the rapidly growing AD population. One of our aims for this study is to stimulate awareness and discussion across disciplines to identify and target patient and caregiver needs related to sexuality/intimacy early in the disease process and before the placement stage.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Frequency of Sexual Behavior/Intimacy Items Within Last Month ($n=162$)*

Key:

- = Never (0)
- ▨ = Rarely (1)
- = Weekly (2)
- ▤ = Daily (3)
- = Constantly (4)

Note: *Results based on smaller sample size due to missing data

Table 1

Baseline Characteristics (N = 162)*

N (%)		Overall (n = 162)		Female (n = 65)		Male (n = 97)		Δ^a ES ^b	
Demographics		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Diagnosis (n=162)									
Probable AD	20 (12.4)								
Possible AD	18 (11.1)								
Mixed AD	124 (76.5)								
Patient Age (years)		76.80 (7.06)		76.20 (7.46)		77.20 (6.78)		1.00	.14
Spousal Age* (years)		73.28 (9.0)		70.67 (8.50)		77.25 (8.40)		6.58**	.73
Patient Age of AD Symptom Onset (years)		71.41 (8.01)		70.77 (8.54)		71.85 (7.64)		1.08	.13
Patient Education* (years)		15.35 (2.87)		14.40 (2.58)		16.00 (2.88)		1.60**	.56
Cognitive/Functional									
MMSE*		20.38 (5.99)		20.33 (5.57)		20.41 (6.29)		0.08	.01
BRDRS*		4.42 (2.94)		4.55 (0.39)		4.32 (0.30)		-0.23	-.08
Neuropsychiatric									
CEQ – Caregiver*		7.18 (3.57)		8.08 (3.55)		5.90 (3.22)		-2.18**	-.64
GDS – Patient*		2.20 (2.31)		2.66 (2.51)		1.87 (2.11)		-0.79	-.35
GDS – Caregiver*		2.73 (2.66)		3.01 (2.99)		2.33 (2.07)		-0.68	-.25
NPI-Q Symptom Severity*		6.22 (5.28)		6.08 (5.03)		6.31 (5.48)		0.23	.04
NPI-Q Caregiver Distress*		6.37 (6.50)		6.55 (6.80)		6.08 (6.05)		-0.47	-.07
Patient Medical History									
Medication Count*		6.11 (3.24)		5.94 (3.18)		6.23 (3.30)		0.29	.09
Co-morbid Conditions*		3.06 (2.11)		3.11 (2.23)		3.02 (2.04)		-0.09	-.04

Notes: SD = Standard Deviation; MMSE = Mini Mental State Examination; BRDRS = Blessed Roth Dementia Rating Scale; GDS = Geriatric Depression Scale; NPI-Q = Neuropsychiatric Inventory Questionnaire

$$^a \Delta = (\text{Male Mean} - \text{Female Mean})$$

$$^b \text{Effect Size} = \Delta / \text{SD } \Delta$$

* Descriptives are based on smaller sample sizes due to missing data.

**
 $p < .01$

Table 2

Sexual Intimacy and Relevant Behaviors

Frequency of Behavior/symptom/feeling in the last month (range = 0-4)	Overall (n=162) *	Female (n=65) *	Male (n=97) *	Δ^a	ES ^b
	Mean (SD)	Mean (SD)	Mean (SD)		
<u>Interest in Sexual Activities (patient)</u>					
Initiates a physically intimate activity. ^c	1.79 (1.31)	1.72 (1.33)	1.83 (1.30)	0.11	.08
Responds positively when spouse initiates a physically intimate activity. ^c	2.24 (1.27)	2.29 (1.21)	2.21 (1.32)	-0.08	-.06
Initiates intercourse?	0.49 (0.88)	0.37 (0.78)	0.57 (0.94)	0.20	.23
Responds positively when spouse initiates sexual intercourse?	0.74 (1.13)	0.87 (1.24)	0.65 (1.05)	-0.22	-.19
<u>Interference with Satisfactory Sexual Relations (patient)</u>					
Is able to stay engaged in sexual activity without getting distracted, losing arousal, etc?	0.65 (1.19)	0.95 (1.42)	0.44 (0.95)	-0.51	-.44
<u>Inappropriate Behaviors or Beliefs (patient)</u>					
Makes inappropriate sexual comments.	0.13 (0.54)	0.06 (0.39)	0.17 (0.62)	0.23	.43
<u>Satisfaction with Intimate Relations (caregiver)</u>					
Patient is able to stay engaged in sexual activity to satisfying completion for the spouse?	0.66 (1.16)	0.42 (0.82)	1.02 (1.45)	0.60	.54

Notes: SD = Standard Deviation

^a Δ = (Male Mean - Female Mean)

^b Effect Size = Δ /SD Δ

^c A physically intimate activity is any activity including kissing, hugging, and intercourse.

* Results based on smaller sample sizes due to missing data.

Table 3
Spearman's Correlations Between Sexual Intimacy and Relevant Behavior Items and
Caregiver Well-Being (CEQ Total Score)

Patient Items	Female Patients (<i>n</i> = 65) *	Male Patients (<i>n</i> = 97) *
	CEQ Total Score	CEQ Total Score
<u>Interest in Sexual Activities</u>		
Initiates a physically intimate activity. ^a	.16	-.13
Responds positively when spouse initiates a physically intimate activity. ^a	.09	-.04
Initiates intercourse?	-.08	-.02
Responds positively when spouse initiates sexual intercourse?	-.21	-.07
<u>Interference with Satisfactory Sexual Relations</u>		
Is able to stay engaged in sexual activity without getting distracted, losing arousal, etc?	-.18	-.05
<u>Inappropriate Behaviors or Beliefs</u>		
Makes inappropriate sexual comments.	.09	.10
Caregiver Items	Female Caregivers (<i>n</i> = 97) *	Male Caregivers (<i>n</i> = 65) *
	CEQ Total Score	CEQ Total Score
<u>Satisfaction with Intimate Relations</u>		
Patient is able to stay engaged in sexual activity to satisfying completion for the spouse?	-.10	-.24
Level of Physical Intimacy with Spouse (EOIPS Item 1)	-.01	-.28
Satisfaction with Physical Intimacy (EOIPS Item 2)	-.29**	-.30

Notes: Spearman's rho used for correlations.

^a A physically intimate activity is any activity including kissing, hugging, and intercourse.

* Results based on smaller sample sizes due to missing data.

**
 $p < .01$

Table 4
Hierarchical Multiple Linear Regression Results

	<i>b</i>	<i>SE b</i>	<i>B</i>
Model 1 (<i>n</i> = 152) *			
Step 1			
Constant	6.980	0.282	
Caregiver (CG) Gender, vs. Male	2.151	0.564	.298 **
Step 2			
Constant	7.045	0.270	
CG Gender, vs. Male	1.767	0.549	.244 **
CG Satisfaction with Intimacy	-1.151	0.302	-.289 **
Step 3			
Constant	7.036	0.276	
CG Gender, vs. Male	1.774	0.552	.245 **
CG Satisfaction with Intimacy	-1.148	0.304	-.289 **
CG Gender x CG Satisfaction with Intimacy	-0.107	0.607	-.013
Model 2 (<i>n</i> = 146) *			
Step 1			
Constant	6.932	0.288	
CG Gender, vs. Male	2.324	0.575	.319 **
Step 2			
Constant	6.459	0.345	
CG Gender, vs. Male	2.383	0.570	.327 **
Mild AD, vs. Severe AD	-1.779	0.682	-.234 **
Moderate AD, vs. Severe AD	-1.029	0.687	-.135
Step 3			
Constant	6.389	0.352	
CG Gender, vs. Male	2.775	0.704	.381 **
Mild AD, vs. Severe AD	-1.985	0.706	-.261 **
Moderate AD, vs. Severe AD	-1.096	0.692	-.143
CG Gender x Mild AD	1.641	1.412	.114
CG Gender x Moderate AD	0.591	1.384	.041
Step 4			
Constant	6.497	0.337	
CG Gender, vs. Male	2.145	0.693	.294 **
Mild AD, vs. Severe AD	-1.741	0.678	-.229†
Moderate AD, vs. Severe AD	-1.023	0.662	-.134

	<i>b</i>	<i>SE b</i>	<i>B</i>
CG Gender x Mild AD	0.758	1.369	.053
CG Gender x Moderate AD	-0.094	1.335	-.006
CG Satisfaction with Intimacy	-1.159	0.306	-.291**

Notes:

Model 1: $R^2 = .089$ for Step 1 ($p < .01$); $\Delta R^2 = .081$ for Step 2 ($p < .01$); $\Delta R^2 = .000$ for Step 3 ($p > .05$).

Model 2: $R^2 = .102$ for Step 1 ($p < .01$); $\Delta R^2 = .041$ for Step 2 ($p < .05$); $\Delta R^2 = .008$ for Step 3 ($p > .05$); $\Delta R^2 = .079$ for Step 4 ($p < .01$).

* Results based on smaller sample sizes due to missing data.

**
 $p < .01$

†
 $p < .05$