

# The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships

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## ABSTRACT

**Background:** Sexuality and intimacy in couples in which one partner is affected by dementia has been widely researched. Few studies have explored these issues in couples where one partner is affected by mild memory impairment (MMI) or mild cognitive impairment (MCI). The objectives of this study were to (1) identify and contrast issues of intimacy and sexuality that spousal caregivers of persons with MMI and dementia may experience, and (2) identify future lines of research in this population.

**Methods:** Fourteen dementia and nine MMI spousal caregivers participated in focus groups conducted between 2008 and 2009 at the Stanford/VA Alzheimer's Research Center. Content analyses were conducted to identify themes.

**Results:** Five themes emerged: communication, marital cohesion, affectional expression, caregiver burden, and ambiguity concerning the future of the relationship. Dementia caregivers reported more difficulties with communication, cohesion, and perceptions of increased burden than their MMI counterparts. Both groups indicated reduced sexual expression due to physical limitations; substitute activities including hand-holding, massaging, and hugging were noted. Both groups reported difficulty anticipating the future of the relationship due to present stressors. While dementia caregivers could consider future romantic relationships with others, MMI caregivers were primarily able to consider future relationships only for companionship and emotional intimacy.

**Conclusion:** Early therapeutic interventions may assist couples in modifying activities, behaviors, and expectations about the future of the relationship. Such modifications may help maintain relationship satisfaction, decrease burden, preserve quality of life, and delay time-to-placement. Extending time-to-placement could have cost savings implications for families and the healthcare system.

**Key words:** dementia, Alzheimer's disease (AD), mild cognitive impairment (MCI), changing relationships, focus groups, qualitative analysis

## Introduction

Despite advances in sexuality and intimacy research in the dementia population, few studies have explored issues of sexuality and intimacy in couples where one partner is affected by mild memory impairment not meeting criteria for dementia (MMI) or mild cognitive impairment (MCI) (Garand *et al.*, 2007). MCI is widely considered

to be a transitional stage between normal aging and the early stages of Alzheimer's disease (AD) in some individuals (Petersen *et al.*, 2001; Petersen, 2005). MMI is a broad diagnostic term applied to those persons who exhibit a memory decline relative to their former level of functioning but who do not currently meet criteria for a clinical diagnosis of dementia (Ishikawa *et al.*, 2006; Weaver Cargin *et al.*, 2006). For the purposes of this paper, all MCI patients were considered to be part of the MMI group. Since MCI and MMI may represent prodromal forms of dementia (Petersen *et al.*, 2001; Petersen, 2005; Ishikawa *et al.*, 2006), there is a need for research that addresses the effect that mild memory changes may have on couples, particularly in the areas of sexuality and intimacy.

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Making the transition to roles of caregiver or care recipient is difficult even for couples with exceptionally healthy relationships, and the MMI period therefore has significant implications for the psychological well-being of both members of the dyad. A couple's satisfaction with their emotional, sexual, and other forms of intimacy may not only affect psychological and emotional health, but may also have longer-term ramifications for decisions about caregiving and placement. Placement decisions also have economic implications for both individuals and the health care system (Leon *et al.*, 1998; Mittelman *et al.*, 2006). However, the dearth of research to date on intimacy – especially sexual intimacy – in couples with a mildly impaired partner makes it difficult to draw clear conclusions about the life cycle of intimacy in early dementia, and about how to help couples maximize their satisfaction with their relationships. Because the field is largely unexplored, this study used focus groups to begin outlining MMI care partners' perspectives on intimacy in their relationships so as to suggest future lines of research and identify opportunities for intervention. For our study purposes, we defined intimacy as “the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship” (Moss and Schwebel, 1993). We defined sexuality as the behavior directly associated with having sexual relations or being sexually aroused, involving both biological and psychological components (Sinnott and Shifren, 2001).

In 2006, Frank *et al.* used focus group methodologies to illustrate the impact that cognitive impairment has on patients with AD and MCI and their caregivers (Frank *et al.*, 2006). This important study found that MCI and AD present a considerable psychological burden on those individuals caring for MCI and AD patients as well as on the patients themselves (Frank *et al.*, 2006). While this paper expanded upon the existing literature by comparing AD and MCI groups, the informant group included several types of caregiving relationships (i.e. spousal, parent-child, and patient-friend) and was therefore unable to explore specific issues concerning intimacy and sexuality. Additional studies have also examined the psychological impact of mild memory loss on caregivers (Garand *et al.*, 2007; Bruce *et al.*, 2008; McIlvane *et al.*, 2008), but there remains a paucity of research that specifically addresses issues of intimacy and sexuality in this population. Currently, the authors of this paper are unaware of any existing studies that have directly investigated intimacy and sexuality in couples affected by memory loss and that have identified similarities and differences in

spousal or spousal-equivalent caregivers (herein referred to as “spousal caregivers”) of persons with dementia and persons with MMI and MCI.

The primary objective of this qualitative study was to identify and contrast issues of intimacy and sexuality that spousal caregivers of persons with mild memory loss and dementia may experience. A secondary objective was to identify future lines of research in this population.

## Methods

### Focus group methodology

Though focus groups were originally developed for conducting market research (Robinson, 1999), they are also used more broadly as a qualitative research tool to investigate a wide array of subject areas in health and social science research (Kingry *et al.*, 1990; Sim, 1998; Robinson, 1999). Focus groups use the interactions between group members to facilitate a deeper discussion of topics that are often considered taboo or difficult to talk about in one-on-one settings (Kitzinger, 1995). The interaction between group members also allows for the development of mutual support as well as for participants to play a role in the direction of the discussion (Kitzinger, 1995). Conversely, focus groups have the potential to suppress minority opinions (Kitzinger, 1994), intimidate shy participants (Beyea and Nicoll, 2000), or be dominated by one or more individuals (Beyea and Nicoll, 2000). An experienced moderator can usually overcome these limitations by helping to guide the discussion and encourage even levels of participation. Groups ideally consist of 4–8 participants and can last between one and two hours (Kitzinger, 1995).

Focus groups are also an established method for conducting research on sensitive topics, particularly in the area of sexual health (Kitzinger, 1994; Robinson, 1999). In 1999, Robinson published work on the use of focus group methodology and provided four examples from sexual health research. Other researchers have used focus groups to investigate a wide range of other sexual health topics including attitudes toward emergency contraception (Hobbs *et al.*, 2009) and sexual health education models (Johnston, 2009; Nakopoulou *et al.*, 2009). Given the body of literature supporting the efficacy of focus groups in sexual health research as well as the limited research available on issues of intimacy and sexuality in dementia and MMI patients and their care providers, we chose to utilize this methodology for the current study.

## Participants

Participants were recruited from support groups at the Stanford/VA Alzheimer's Research Center. Spousal caregivers were eligible to participate in the dementia caregiver focus group if an affected partner had a diagnosis of dementia based on the Alzheimer's Disease Research Centers of California (ARCC) manual for diagnostic criteria, which was adapted from DSM-IV (APA, 1994). Spousal caregivers were eligible for the MMI caregiver focus group if an affected partner had a diagnosis of one of the following: mild cognitive impairment meeting either Petersen (Petersen *et al.*, 1999) or NIA Cooperative Study criteria (Grundman *et al.*, 2004), mild neurocognitive disorder (APA, 1994), or questionable cognitive impairment (includes age-associated memory impairment (Crook *et al.*, 1996) and age-related cognitive decline (APA, 1994)). All patients were diagnosed by consensus reached by a team of clinicians at the Stanford/VA Alzheimer's Research Center based on diagnostic guidelines established by the Alzheimer's Research Centers of California (ARCCs). Twenty-three spousal caregivers of patients with either dementia or MMI participated in this study and a total of four groups (two for dementia spouses followed by two for MMI spouses) were conducted between 2008 and 2009.

The protocol was approved by the Stanford University Committee on Human Research and the Palo Alto Veterans Affairs Medical Center Research and Development Committee. All participants involved in the study provided informed consent. Following consenting procedures, each participant was given a numbered card to display during the group interview for transcription purposes. Two research observers transcribed each of the focus group sessions, and their transcripts were reviewed against each other to ensure content accuracy and control for observer bias. Both observers wrote down all conversations that occurred in order to provide a complete record of the sessions and guard against bias in selecting "relevant" points for transcription. All but one of the focus group sessions were recorded on laptop computers. Each focus group interview was conducted by one of the authors, a Board Certified Clinical Nurse Specialist in Adult Psychiatric Mental Health, and lasted approximately two hours.

## Measures

The moderator utilized prompt questions that addressed issues of intimacy and sexuality (see Appendix A and Appendix B). These questions were developed by two of the authors based on previous research and clinical experience (Mittelman *et al.*, 2003). In addition to the

focus group guide questions, the following sample demographics were collected: age, years of education, gender, ethnicity, marital status, length of relationship with the patient, living arrangement, and approximate year of the patient's diagnosis.

## Analyses

Transcripts from each focus group session were reviewed and compared to verify content accuracy. Data were preliminarily analyzed using modified indexing guidelines from Frankland and Bloor to identify themes for each focus group (Frankland and Bloor, 1999; Halcomb *et al.*, 2007). This indexing method, which has been proven to be successful by other researchers (Saulnier, 2000; Edwards *et al.*, 2001; Leask *et al.*, 2006), consisted of reading the transcripts and extracting words or labels that related to the content. The process was then repeated several times to allow for the emergence of new themes and/or the combining of existing themes to create final categories.

Following the completion of all focus group sessions, a grid technique was used to compare and contrast themes between the dementia and MMI groups (Halcomb *et al.*, 2007). This involved the placement of themes from the preliminary analysis across the horizontal axis and the two respondent groups (i.e. dementia and MMI) down the vertical axis. Examples from the transcripts from each focus group populated the cells. This process provided a systematic method of categorizing all statements.

## Results

Fourteen dementia and nine MMI spousal caregivers participated in this study. All but two couples were living together at the time of their participation; one spousal caregiver had recently been widowed and another patient had been placed (i.e. relocated to a nursing home) two months prior to the session. One couple was not married at the time of the focus group sessions, but had been in a domestic partnership for 20 years. Dementia group respondents were caring for individuals diagnosed with AD ( $n = 12$ ), frontal temporal lobe degeneration ( $n = 1$ ), and mixed diagnosis including dementia with Lewy bodies and vascular dementia ( $n = 1$ ). MMI group respondents were caring for individuals diagnosed with mild cognitive impairment ( $n = 3$ ), mild neurocognitive disorder ( $n = 4$ ), and questionable cognitive impairment ( $n = 2$ ). The majority of the spousal caregivers were Caucasian (93% of AD group and 100% of MMI group) and female (71% of dementia group and 78% of MMI group). As a whole, spousal caregivers were highly educated, with an average education

of 16 years for the dementia group (SD = 2; range = 13–22) and 18 years for the MMI group (SD = 2; range = 16–20). The mean age was 75 years for both groups (dementia SD = 8; dementia range = 62–87; MMI SD = 8; MMI range = 58–87). On average, dementia patients received their diagnosis two years prior to the focus group sessions while MMI patients were diagnosed more recently – an average of 10 months prior to their respective focus group sessions. The mean length of relationship duration was 44 years for the dementia group (SD = 16; range = 22–62) and 40 years for the MMI group (SD = 17; range = 10–60).

### Communication in intimate relationships

Participants in the MMI and dementia focus groups indicated an alteration in communication within the relationship after the patient was diagnosed.

#### DEMENTIA FOCUS GROUPS

Several participants in the dementia groups noted that the ability to engage bilaterally in conversations with their affected partners was virtually absent. One 69-year-old female participant stated, “Real talking is not there since he can’t remember.” A 70-year-old male participant attributed his poor relationship quality to a lack of communication (despite an improved sexual relationship), stating that the “relationship is not better because there is still no communication.” Notably, some participants also revealed that they had sought marital counseling for communication difficulties prior to their partners’ diagnoses of dementia. One participant said, “We went long before the illness ... there was a communication problem.” These counseling sessions were reported to be unsuccessful. Some of these spouses also attributed relationship problems to external factors such as alcohol use, stress, medications, and hearing problems, but did not consider memory loss as the source.

#### MMI FOCUS GROUPS

Some MMI group participants reported that communication, while diminished in quality, was not entirely absent. One 58-year-old participant said that he still engaged in conversation with his partner and received feedback when he needed it. Others noted that they preferred to keep thoughts and feelings to themselves and expressed feelings of exasperation and tension related to communication troubles. An 82-year-old female respondent stated, “I find that I get frustrated by trying to explain something to him. I just don’t bother but I know it’s not a good habit.” Some respondents verbalized that the natural flow and ease of communication

was affected. A few participants noted that they were inclined to moderate their conversation by simplifying and/or holding back complex thoughts and feelings in order to avoid frustration.

While participants in the MMI group were more inclined to censor and adapt, the perception that communication was intact and preserved to some degree, was still present. As with the dementia group, a few MMI participants also sought relationship counseling for communication difficulties prior to a formal diagnosis of memory impairment. Feelings of frustration and irritation with changes in communication were commonly expressed in the MMI spousal caregiver group.

### Alterations in marital cohesion

#### DEMENTIA FOCUS GROUPS

Spousal caregivers of dementia patients overwhelmingly reported diminished marital cohesion, or the degree to which they engage with his or her partner (Garand *et al.*, 2007). Several respondents expressed that their relationships have regressed into parent-child relationships, a change that negatively affected their intimate engagement in both emotional and sexual dimensions of the relationship. They cited over-dependence and the inability of the dementia partner to make decisions as the causes of the relationship change. Some expressed loneliness and sadness over the loss of relationship rituals. One participant noted that “the magic time was gone. And [she and her spouse] never replaced those rituals.” Others voiced a greater appreciation of their partners and even enhanced intimacy. One female participant stated:

“As I became aware of the reality of the disease, I think that I had a different kind of intimacy – much kinder, more caring about him ... The intimacy grew because of me. I did a full cycle of understanding him better and caring for him better.”

A few participants indicated an increase in verbal and non-verbal expressions of affection towards the unaffected spouses. One 69-year-old participant stated that her spouse tells her that he loves her more now than before he was diagnosed with memory loss. However, most of the participants perceived a significant alteration in the cohesion of their relationships.

#### MMI FOCUS GROUPS

Contributions from MMI spousal caregivers revealed a less severe loss of marital cohesion. Spousal caregivers of MMI patients expressed that they were still in the process of discovering and accepting the reduced abilities of their partners.

Some expressed feelings of regret that they had not noticed symptoms of memory loss sooner (i.e. inability to balance the checkbook, poor work performance, and early mood and behavioral changes that resulted in the temporary separation of one couple). Some participants verbalized a continued respect for their partners, particularly surrounding premorbid professional and personal accomplishments. A 72-year-old male participant stated, "When I was younger, I was more self-centered. My work was everything and my wife took care of family decisions." He further reflected that he was "surprised when [he] looked back at how immature [he] was in the marriage." He maintained that his spouse managed all the domestic activities, including planning for their children's college tuition, etc. Some participants verbalized annoyance and frustration over their partners' memory changes, but also a growing sense of acceptance. Several members of the group voiced a sense of companionship but noted that relationship activities now required modification. For example, some participants noted that movies had to be selected carefully to avoid complicated plots that could frustrate or agitate the affected partner. Some respondents also verbalized a loss of intellectual interaction which affected the perception of marital cohesion.

### Affectional expression

#### DEMENTIA FOCUS GROUPS

The dementia group generally, though not universally, reported a decrease in affectional expression, defined as "the degree to which the respondent is satisfied with the expression of affection and sex in the relationship" (Garand *et al.*, 2007). If physical demonstrativeness, e.g. sexual intercourse, was not present prior to the dementia diagnosis, then a change was generally not reported. Impotence and other health-related conditions were reasons provided by some members of the dementia groups for limited or absent sexual relations both pre- and post-morbid.

Three spousal caregivers indicated preservation of their premorbid sexual relationships. For example, one 76-year-old male respondent described it as "still somewhat normal." Many participants described a shift away from sexual activities towards other modes of demonstrativeness including hand-holding, kissing, cuddling, and touching. Some participants reported increased demonstrativeness by their partners. One participant noted that "What's changed now is that he wants to give me a back rub and spontaneously hugs me. And he never used to do that ... It seems that he is gentler and much more affectionate." The other participants

either described a loss of sexual expression or the need to encourage reciprocation once they had initiated an affectional action. One respondent stated: "I do the hugging, kissing, etc. I have to say, 'Hug me back.' He doesn't demonstrate a lot of affection. Even though he's caring – he's accepting but doesn't initiate." Other participants indicated a lack of desire to respond to the affected partner's physical advances either because they are no longer "in love" or because their partners no longer recognize them as spouses. One participant said, "When my husband thinks that I am his sister, it's hard for me to get 'turned on'."

#### MMI FOCUS GROUPS

MMI participants verbalized similar concerns. Physical limitations significantly contributed to reduced or eliminated sexual activity in this population. One male participant described his relationship as "like brother and sister." While some respondents expressed feelings of resignation in response to the decline in sexual activity, others noted improved sexual relations following diagnosis. One male participant reported that the changes his role as a caregiver required of him emotionally led to improved physical intimacy (despite decreased libido due to depression) and increased responsiveness from his MMI partner. He stated, "We engage in sexual intercourse a couple of times a month. If I am interested, she is interested ... I affirm her more and that has made our sexual relationship better." Substitute activities such as massaging, sitting close, holding hands, and touching were also cited by this group as preferred modes of affection. A 77-year-old female respondent said, "We do a lot of massaging – he rubs my back. This is our way of staying in physical contact. Before we go to sleep, that's our routine."

### Perception of spousal caregiver burden

#### DEMENTIA FOCUS GROUPS

Nearly all dementia group respondents verbalized some degree of psychological and emotional burden in caring for the affected spouse. Caregiver burden is a multidimensional process that can affect many areas of life (Zarit, 2008) and is defined by George and Gwyther as "the physical, psychological, or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (George and Gwyther, 1986). Several participants noted an increased burden in managing daily household activities. One female respondent noted that she feels like "superwoman." She expressed feeling overwhelmed with the responsibilities that she now assumed including feeding and showering her partner, and

dealing with his incontinence. Some participants reported an increase in their partners' level of dependence. One participant noted that her spouse "doesn't want [her] out of his sight. He burst into tears because [she] couldn't spend the night in the hospital." Another participant verbalized that she attempts to moderate the dependence by continuing to seek input from her husband regarding household decisions. Several dementia focus group participants expressed frustration and anger regarding their situations. One participant noted that she felt "cheated" out of her life-partner. Another participant reported that she becomes very angry and frustrated and that she needs "to be away from [her spouse] a bit so [she] can figure out what to do." Another respondent admitted that she wished "this would all be over."

#### MMI FOCUS GROUPS

Participants in the MMI group also perceived spousal caregiver burden but to a lesser degree than the dementia focus group participants. Several participants reported that dealing with their partners' memory problems on a daily basis was stressful. They described feeling impatient, depressed, and anxious regarding their partners' memory changes. This group almost universally acknowledged the importance of self-care as an antidote to spousal caregiver burden. There was a consensus among this group that self-care was necessary to avoid becoming "unhealthy" and "socially withdrawn." Many participants prioritized self-fulfilling activities to cope with perceived relationship burden such as attending bridge class, going to the gym, volunteering, and seeing friends. Others mentioned working less and relying on family members for emotional support.

#### **Ambiguity concerning the future of the relationship**

##### DEMENTIA FOCUS GROUPS

Several participants in the dementia groups reflected on their uncertainty and emotional ambiguity regarding the future of their relationships. One participant commented that she viewed placement of her spouse in a facility as "the end" of the relationship. Other participants expressed resignation over the course of the disease and the eventual impact on their relationships. One respondent noted that she "would miss him but [she] would get over it." Other respondents commented that they refrain from envisioning the future and prefer to focus on the present. One participant noted, "I have so many irons in the fire right now that I can't even think of the future."

Another respondent verbalized that she "can barely make it through one day."

When asked to consider future intimate relationships with persons other than a spouse or spouse-equivalent, the majority of the dementia group participants indicated openness to external relationships. Several respondents expressed a desire for companionship and for more satisfying emotional and/or physical interaction. A few participants noted that this would provide both a perceived relief from responsibilities and a boost to their emotional and physical well-being. One female respondent noted that "It would be nice to have someone make [her] feel good again." Another participant commented that she "wouldn't have to be a hag anymore." Some participants expressed that they were not interested in pursuing relationships until their partners were deceased.

#### MMI FOCUS GROUPS

Participants in the MMI group expressed that they were handling the ambiguity of the future by remaining focused on the relationship in the present. One male participant noted that he had heavily focused on researching ways to delay the disease progression in his partner. Another participant stated that one should be "grateful for what you have left and realize that you won't get back what you had." Other participants expressed a great deal of concern about the future of the relationship, particularly concerning the deterioration of their partner and the possibility of placement. One participant acknowledged his denial of his partner's eventual physical deterioration. He stated, "We're at a level plateau right now and we're just dealing with one day at a time. Later on I might regret this, but it's okay for now." Another respondent who had recently moved into a retirement community with her husband stated, "If something happened to us, I worry terribly that things would change. Our affairs are not in order. I worry about how much I would miss him."

When asked to consider future, intimate relationships with persons other than their spouse or spouse-equivalent, several MMI focus group participants acknowledged that they would like more emotional intimacy (i.e. conversations) but that they were not seeking anything beyond their primary relationships at this point. An 82-year-old participant said, "I would be interested in someone else – not sexually – but for communication. It would be for emotional intimacy and talking more than a physical relationship." Another respondent echoed that sentiment, stating, "I don't feel a strong need at the moment to have sexual or romantic

relationships, but I do need more friends.” A 72-year-old male respondent said that he would only move in that direction after his partner was in a “vegetable state.”

## Discussion

The impact of dementia on sexuality and intimacy in spousal relationships has been well investigated (Litz *et al.*, 1990; Wright, 1991; Davies *et al.*, 1992; 1998; Derouesné *et al.*, 1996; Kuppaswamy *et al.*, 2007; Simonelli *et al.*, 2008). In 1992, Davies *et al.* discussed a wide array of sub-topics including the higher incidence of erectile problems in Alzheimer’s disease patients, concerns about changing sexual behavior as a result of disease progression, inappropriate sexual behavior, and the ongoing need for touch. The authors concluded that while AD patients and their partners will have sexual needs and feelings, the disease is likely to have a significant impact on sexual behavior (Davies *et al.*, 1992). In 2003, Mittelman *et al.* published results from focus groups they conducted in order to further explore the particular issues that couples faced when affected by dementia, Alzheimer’s type (Mittelman *et al.*, 2003). This research revealed overwhelming losses within many areas of participant relationships including communication, closeness, reciprocity, intellectual stimulation, and assistance with decision-making. Difficulties with sexual experiences, resulting from trouble remembering appropriate actions, trouble with sequencing, and physical limitations, were also reported.

The primary objective of this current study was to identify and contrast issues of intimacy and sexuality that spousal caregivers of persons with dementia and MMI impairment may experience, particularly in terms of the effects of cognitive loss on relationship quality. We also sought to identify future lines of research in this population. Through the use of focus groups, we had the opportunity to explore attitudes, beliefs, and experiences from our respondents that may have been less accessible in an individual interview format (Kitzinger, 1995). Additionally, the focus groups provided an open forum for our respondents to discuss issues of sexuality and intimacy with candor and frankness. While our results indicate that both caregiver groups perceive an impact on their intimacy and sexuality due to their partner’s memory loss, our study suggests that spouses caring for people with mild memory loss generally experience a less severe negative impact on these relational areas than their dementia group counterparts. It is worth noting, however, that a few participants in both groups

indicated improvements in post-morbid emotional engagements.

In general, dementia group respondents expressed the fact that bilateral communication was nearly absent, whereas spousal caregivers of persons with MMI reported that they continued attempting to engage with their partners, and sometimes modified previous communication patterns (e.g. complexity or length) to facilitate understanding and satisfaction. Of particular interest is our finding that some respondents in both groups sought relationship counseling for communication difficulties prior to formal diagnoses of memory impairment. It is possible that these relationship disturbances may be associated with incipient memory loss at the preclinical stage.

Research indicates that pre-morbid changes may include reduced verbal expression (Cuetos *et al.*, 2007) and alterations in personality (Balsis *et al.*, 2005). Balsis *et al.* found that changes in personality such as increased rigidity, growing apathy, increased egocentricity, and impaired emotional control often precede a diagnosis of dementia (Balsis *et al.*, 2005). This study concluded that individuals became more self-centered and inflexible prior to a dementia diagnosis (Balsis *et al.*, 2005). Additionally, Apostolova and Cummings (2007) found that neuropsychiatric symptoms are commonly observed in MCI patients. Depression, apathy, and anxiety are consistently identified as the most common behavioral problems in MCI, and these findings could be used to help identify impending dementia (Apostolova and Cummings, 2007). While these studies did not directly link cognitive, behavioral, and personality changes to marital troubles, the presence of such problems may result in communication barriers which would likely contribute to relationship challenges. Further research is necessary to investigate the presence of relationship challenges prior to a formal diagnosis of memory impairment. If supported by future studies, sudden difficulties in long-term intimate relationships may serve as a pre-diagnostic marker for possible memory problems and may call for promoting increased awareness among clinicians and the development of new therapeutic approaches in older couples seeking counseling for marital communication difficulties.

The dementia group respondents perceived a significant alteration in the cohesion of their marriages, particularly through the loss of relationship rituals. While the MMI respondents also noted diminished marital cohesion, these respondents were more likely to note that they were discovering and gradually accepting the reduced abilities of their partners. The results from the focus groups suggest that there is still a perception of

intact marital cohesion in the partners of those affected by MMI. Promoting the acceptance of changing relationship rituals as soon as possible after a diagnosis of memory impairment could help facilitate a stronger sense of marital cohesion as memory problems progress.

Both the dementia and MMI groups reported significant alterations in affectional expression, with the exception of those who experienced difficulties prior to the onset of memory loss. Thus, affectional expression emerges as a prime candidate for attention in interventions supporting spousal caregiving relationships in which one partner is affected by any degree of memory impairment. This study's results suggest that future interventions designed to support spousal caregiver couples should give consideration to the very high likelihood of decreased affectional expression and work towards modification of care partners' expectations as well as the importance of substitute activities.

Results of the focus groups suggest that both groups experienced significant spousal caregiver burden. In a 2005 study, Garand *et al.* demonstrated that higher subjective caregiver burden was significantly associated with psychiatric morbidity in spouses of persons with MCI (Garand *et al.*, 2005). Findings from both the aforementioned Garand study as well as the present study reveal the importance of assessment and evaluation of caregiver burden even in dyads affected by milder forms of memory impairment, such as MCI or MMI. As suggested by Garand *et al.* (2005), therapeutic interventions may need to be developed that target this at-risk caregiver population to reduce psychiatric morbidity. Such approaches could include both individual and couples counseling with consideration of underlying memory problems, as well as the development of new relationship rituals to compensate for the emotional, cognitive, and functional decline of the affected partner. Initiation and/or maintenance of self-care activities should also be emphasized.

There were also variations within and between the groups in participants' ability to consider the future of the relationship. The majority of the dementia group participants anticipated and accepted forthcoming relationship changes, including placement. While most dementia group participants had come to terms with the eventual outcome of the disease, they also expressed feeling overwhelmed by day-to-day responsibilities and were focused on survival in the present. Although MMI group participants were also focused on the present, the reasons were different. MMI spousal caregivers were in the process of investigating disease prevention strategies, and/or trying to enjoy

their relationship in its present state. Unlike the dementia spousal caregivers, MMI participants maintained a willingness to invest time and effort in the relationship, indicating a perception of hopefulness for the future.

When asked to consider new relationships, most of the dementia group participants were open to this idea but could not actively think about implementing it due to high stress levels. Spousal caregivers of MMI patients, on the other hand, said they would be open to new relationships primarily for companionship and emotional intimacy, rather than physical intimacy. Therapeutic interventions in the MMI population could improve relationships in the present and lay the foundation for a modified but sustainable relationship in the future, should memory problems progress to dementia. These interventions may be adapted for use either in couples' counseling or in a support group setting.

There were several limitations of this study that deserve acknowledgement. The individuals that participated in the focus group sessions comprised a homogenous, small sample. Our cohort was highly educated and mostly Caucasian which may not be representative of the broader community. Further investigation of issues of intimacy and sexuality in spousal caregivers of persons with mild memory loss and dementia ought to include a larger and broader social and educational sample. Additionally, since the majority of our sample consisted of female spousal caregivers, gender-specific differences could not be determined. Future research on this topic should be considered. As previously discussed, there are also inherent biases and weaknesses in focus group methodology. Finally, the clinician who moderated the focus group session was known to the participants. While this bias could limit the reliability of the focus group findings, it can also be viewed as an advantage. Most respondents had an established rapport with the moderator prior to the focus group sessions and may have felt more comfortable disclosing personal information in a group interview format.

In conclusion, this is the first study to our knowledge that specifically explores issues of intimacy and sexuality in the context of a dyadic, intimate relationship that has been impacted by either mild memory impairment or dementia. It is our hope that these broad findings will increase clinicians' awareness and stimulate future research initiatives in the development and evaluation of early therapeutic interventions. Such interventions would strengthen spousal relationships, preserve quality of life for couples affected by MMI and dementia, and delay time-to-placement, thereby decreasing

the financial burden for both families and the health care system.

### Conflict of interest

None.

### Description of authors' roles

Helen D. Davies conducted all focus group sessions, oversaw the data analysis, contributed to writing and editing the paper, and is the co-principal investigator (PI) of the study. Lori A. Newkirk recorded transcripts for focus group sessions, analyzed the data, conducted literature searches, and contributed to writing and editing the paper. Christiane B. Pitts designed the study, recorded transcripts for focus group sessions, analyzed the data, conducted literature searches, and contributed to writing and editing the paper. Christine A. Coughlin and Sneha B. Sridhar recorded transcripts for focus group sessions, conducted literature searches, and assisted with editing the paper. L. McKenzie Zeiss conducted focus group literature searches and was involved in the early conceptualization of the study. Antonette M. Zeiss assisted with editing the paper and is the co-PI of the study.

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## Appendices

### Appendix A: Focus Group Questions, Session I

- I. What are the biggest changes in sexuality and intimacy since your partner was diagnosed with dementia/mild memory impairment?
  - a. Has the role of intimacy in your relationship changed? (E.g., was once important but is not so much now, emotional or physical intimacy less or more important, etc.)
- II. What difficulties and/or challenges have you faced in regards to sexuality and intimacy since your partner was diagnosed with dementia/mild memory impairment?
- III. What challenges do you anticipate in the future?
- IV. Consider other relationships in the future.
  - a. How do you feel about a person who enters into an intimate relationship with someone else when his/her partner has developed dementia/mild memory impairment?
  - b. How do you perceive that choice?
  - c. How do you think you would feel if your partner were to develop an intimate relationship with someone else?

- d. Do you consider entering into an intimate relationship with someone else?
- e. If you have adult children, do you feel that your children would have difficulty with this situation?

## Appendix B: Focus Group Questions, Session II

### I. Intimacy

- a. How would you define intimacy as it was actualized in your relationship before your partner was diagnosed with dementia/mild memory impairment?
- b. How has your working definition of intimacy changed once your partner was diagnosed with dementia/mild memory impairment?
- c. How would you define sexuality as it was actualized in your relationship before your partner was diagnosed with dementia/mild memory impairment?
- d. How has your working definition of sexuality changed once your partner was diagnosed with dementia/mild memory impairment?

### II. Communication

- a. How many of you experienced issues with communication in your relationship shortly before your partner was diagnosed with dementia/mild memory impairment? (show-of-hands)
- b. How many of you sought counseling for issues with communication shortly before your

partner was diagnosed with dementia/mild memory impairment? (show-of-hands) If yes, what issues were raised? How did your partner respond to the counseling? Was the counseling beneficial?

### III. Coping

- a. (*Dementia Group Only*) Discuss this statement by a caregiver, 'What do you want me to do? Sit here and watch you?' Do you have feelings of anger? How are you coping with feelings of anger?
- b. (*Mild Memory Impairment Group Only*) Have you experienced feelings of anger towards your partner? If so, how are you coping with these feelings?
- c. How do you feel that you are coping with the changes in intimacy that have occurred since your partner was diagnosed with dementia/mild memory impairment?
- d. Do you feel that you are caring for your own emotional needs?
- e. Describe your coping strategies.
- f. (*Dementia Group Only*) What do you see in the future for yourself and your partner? Is it difficult to imagine the future right now?

### IV. Other

- a. (*Mild Memory Impairment Group Only*) Have there been any changes in your relationship rituals since your partner was diagnosed with mild memory impairment? That is, have you stopped or altered some activities that you used to do together on a regular basis? For example, reading the paper or going for walks.