

The Influence of Mild Cognitive Impairment (MCI) on Marital Relationships

Brianne L. Winston

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Dr. Karen A. Roberto, Chair

Dr. Rosemary Blieszner

Dr. Shannon E. Jarrott

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## Abstract

The purpose of this study was to examine the influence of mild cognitive impairment (MCI) on marital relationships. MCI refers to age-related decline in memory and other cognitive processes that do not necessarily interfere with daily activities or the maintenance of social relationships with others (Petersen et al., 1999). Using social exchange theory as the theoretical framework to guide this qualitative study, aspects of the marital relationship explored from the non-impaired spouses' perspective were couple interaction, intimacy, and the division of household labor.

In-depth interviews were conducted with five husbands and five wives (M age = 76.6 yrs., S.D. = 6.64). Open-ended interview questions that focus on issues specific to the marital relationship included: (a) range of activities participated in as a couple, (b) ways of showing care or affection toward one another, and (e) management of everyday life. In addition to participating in the semi-structured interviews, the spouses completed three standardized scales (e.g., *Revised Memory & Behavior Problems Checklist*, *Zarit Burden Interview*, *Center for Epidemiological Studies-Depression Scale*). Their responses to these measures provided information about the memory and behavioral changes of the elder as it related to the outcomes for and responses of the spouse.

Spouses noted both change and stability within their marriages. They expressed "mixed emotions" concerning the influence of MCI on both them as

individuals and on their relationship. Husbands' responses focused on the negative relationship outcomes (e.g., frustration, stress) associated with caring for a spouse with memory loss; however, wives reported higher levels of burden and depression on the standardized measures than did the husbands. Gender differences were found regarding how husbands and wives view their roles in context to the caregiving situation, as well as how they adapt and cope. Longitudinal research is needed to examine the changes in the dynamics of these late-life marital relationships over time.

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# THE INFLUENCE OF MILD COGNITIVE IMPAIRMENT (MCI) ON MARITAL RELATIONSHIPS

## CHAPTER I

### Introduction

When faced with a diagnosis of mild cognitive impairment (MCI), families are often shocked and terrified because they are uncertain of the diagnosis and the changes that might occur in their loved one (Kuhn, 1998). There is a lack of a definitive diagnostic terminology for what their family member is experiencing. Often, they are frustrated by the changes in memory experienced by their family member, as well as the ambiguity that the future holds. With diseases such as Alzheimer's or Parkinson's, health care providers recommend that families seek out information and suggestions for understanding and coping with the illness (Garwick, Detzner, & Boss, 1994). With MCI, health care professionals are still unclear of the manifestations of the diagnosis and are unable to refer patients and families to documents about MCI specifically. Not knowing what changes the future may hold is often difficult for family members. This is particularly true for spouses, as their daily lives are influenced by changes in their marital roles and relationship. When one member of the spousal dyad experiences cognitive decline, the other often takes on the caregiving role, despite the likelihood of experiencing adverse effects such as depression, burden, or stress. For persons with MCI, the non-impaired spouses may take on a managerial role, in which the intention is to help "manage" the emotional and behavioral changes of their partner with MCI. Furthermore, they may also be experiencing personal health problems, which may increase feelings of burden, stress, and depression (Navon & Weinblatt, 1996).

The purpose of this study was to examine the influence of MCI on marital relationships. Specific areas addressed included intimacy and household responsibilities within the spousal dyad. Examination of these interactions can inform researchers and clinicians about the issues and concerns that couples have at this early stage of cognitive impairment. In this introductory chapter, I provide a brief overview of the clinical manifestations of MCI. I also provide an explanation of the theoretical framework through which I view spousal relationships in later life in the context of dealing with MCI.

### *Mild Cognitive Impairment (MCI)*

Mild cognitive impairment (MCI) refers to age-related decline in memory and other cognitive processes. It is a relatively new diagnosis used to identify cognitive changes that do not necessarily interfere with daily activities or the maintenance of social relationships with others (Petersen et al., 1999). Several criteria for MCI have been suggested (Palmer, Fratiglioni, & Winbald, 2003); however, there is no “gold standard” or specified criterion for diagnosing MCI. The criteria put forth by Petersen and colleagues (1999) are the most widely applied in clinical practice and research. They suggest the presence of MCI when: (a) there is a complaint of memory loss, (b) minimal interference of activities of daily living is apparent, (c) normal cognitive functioning is evident, (d) memory loss is uncharacteristic for the age of the person, and (e) there is not a diagnosis of dementia.

### *Prevalence of MCI*

MCI is often a precursor to the development of Alzheimer’s disease (AD). Morris and colleagues (2001) proposed that MCI progresses to AD at a rate of 10% to 15% per

year. Yesavage and colleagues (2002) challenged the validity of this rate and suggested that changes over a year are evident but gradual, meaning that the progression from MCI to dementia does not occur abruptly. Researchers use different approaches for determining MCI prevalence and its relation to AD. Testing of community-based random samples is one common approach used to determine the prevalence rates of MCI. Using the diagnostic criteria provided by Petersen and others (1999), Hanninen and colleagues (2002) administered a series of tests designed to assess cognitive abilities (e.g., Clinical Dementia Rating Scale-modified, Boston Naming Test, Trail Making test, and Mini-Mental State Examination [MMSE]), memory deficits, language fluency and cohesiveness in a community sample of 806 older individuals. They established an MCI prevalence rate of 5.3% for this community-based sample. Self-reported psychiatric illness and history of cerebral infarcts was associated with the appearance of MCI-related criteria. Furthermore, persons with MCI tended to be less educated and older than those who did not receive an MCI diagnosis. More educated persons are perhaps more aware of techniques that can be used to mask their cognitive declines. For example, employed persons with MCI may be able to rely on a secretary to keep them informed of meetings and deadlines which allows them to be able to continue managing their work responsibilities efficiently.

The tools used to assess MCI may contribute to reports of its prevalence. For example, Busse and colleagues (2003) assessed 1,045 participants living in the community, using four diagnostic approaches: (a) MCI criteria as described by Petersen and colleagues (1999); (b) Ageing-Associated Cognitive Decline (AACD) proposed by Levy (1994); (c) AACD-modified, which excluded the section involving patients'

subjective memory complaints; and (d) Mini Mental State Examination (MMSE) score alone. Commonly used to screen for cognitive impairment, the MMSE consists of items that test areas of functioning including: (a) orientation, (b) registration, (c) attention and calculation, (d) recall, and (e) language. The maximum score is 30, with a score of 23 or lower indicating cognitive impairment (Folstein, Folstein, & McHugh, 1975). Based on the above diagnostic approaches, the authors concluded that prevalence rates differed depending on the criteria used to determine the presence of MCI. Using Petersen and colleagues' (1999) criteria, they found that the prevalence rate for MCI was 3%. Basing the diagnosis on AACD criteria, the prevalence of MCI was 9%; however, when omitting the subjective memory complaints (AACD-modified), the prevalence increased to 20%. Finally, using the MMSE exclusively as a criterion for determining MCI prevalence was 23%, which was comparable to the AACD-modified criteria. The authors concluded that assessment tools control the outcomes of the results and suggested prevalence of MCI.

Overall, the benefit of population-based sampling is that it is a more time-efficient approach compared to recruitment of persons from outpatient clinics (Hanninen et al., 2002). However, there are limitations to using this approach, including underestimation of the prevalence of MCI due to sampling and assessment errors (Busse et al., 2003; Hanninen et al., 2002). Busse and colleagues (2003) concluded that, in general, persons believed to be at higher risk for developing MCI (i.e., those less educated and with lower MMSE scores) are also less likely to participate in community assessments. Clinicians and practitioners need to increase awareness of memory impairments to the larger population to ensure accurate screening outcomes; however, this could lead to the over-diagnosing of MCI. These current-screening techniques may be hypersensitive

to diagnosing MCI, which introduces a need for follow-up studies of random, population-based samples to confirm the prevalence of cognitive decline, as well as more advanced MCI screening techniques.

Another approach used to identify the prevalence of MCI is through the recruitment of individuals from outpatient centers, such as memory clinics. This study utilized this recruitment strategy. Using a quantitative analysis, Petersen and colleagues (1999) clinically characterized persons with MCI using both cross-sectional and longitudinal designs. Their sample consisted of three groups of participants: (a) individuals with MCI, (b) healthy control individuals, and (c) persons with mild AD. The recruitment of participants was from an Alzheimer's disease center. Their findings suggest that individuals with MCI are at an increased risk for developing AD at the rate of 10% to 12% per year. After one year, all participants were re-examined for indications of cognitive impairment. Some participants moved from category to category, even the extreme case of going from healthy to mild AD. The only group that did not move in and out of a category was individuals initially in the mild AD group.

Xu and colleagues (2002) examined screening methods for MCI using a combined testing approach. By combining the MMSE and the Cognitive Capacity Screening Examination (CCSE), the researchers sought to increase the accuracy of the prevalence rates of MCI. During their six-year longitudinal study, 84 of the original 351 participants developed dementias of different types over a period of three to six years. The authors concluded that combining the MMSE and CCSE measures had optimal use and they suggested that this combination of assessment tools provided a "gold standard" for the screening of MCI among non-demented elderly populations (Xu et al.,

2002); however, future studies are necessary to confirm the reliability and validity of this approach.

Memory clinics provide the opportunity to study those with MCI and their possible progression rates to AD in a more concrete way by identifying those with existing memory problems (Xu et al., 2002). However, samples recruited from outpatient clinics also have limitations. Participants recruited from outpatient clinics are aware of their cognitive changes, often more educated, and perhaps more open to receiving assistance. It is possible for those individuals with less education and financial support to remain undiagnosed throughout this condition because they are less likely to seek help from outpatient memory clinics. Community-based screening is optimal for identifying educationally diverse populations of persons with MCI.

### *Family Caregiving*

Persons with mild memory impairments and their family members are often unaware of the trajectory of the condition. Most of the research on caregiving and cognitive impairments has focused on families coping with moderate to severe declines (Bedard et al., 1997; Dura et al., 1990; Garwick et al., 1994; Kramer, 1997; Rudd et al., 1999; Wright, 1993, 1994). Studies that specifically examined family care issues of persons with mild cognitive decline are limited and most often addressed the response of families caring for persons in the early stages of AD. For example, Garwick, Detzner, and Boss (1994) interviewed 38 families in which the primary caregiver or helper was the spouse and the patient was receiving home care. All patients were in the mild to moderate stage of AD. Four major themes were evident throughout the family interviews: (a) uncertainty of the diagnosis, (b) awareness that something was wrong at

the onset of the disease, (c) loss of interaction with other family members, and (d) ambiguous changes in family relationships. Most families referred to the cognitive impairments as “it,” which is a common avoidance technique for persons who are in shock and disbelief (1994). Family members, as well as the patients, appeared overwhelmed by the current changes in cognitive abilities and were fearful of what the future may hold. They did not want to admit the abnormality of this memory decline and held on to their beliefs that the changes that their loved one was experiencing were a normal part of the aging process.

Similarly, Kuhn (1998) interviewed 20 families of persons in the early stage of AD, which they characterized as a loss of working memory and some personality changes. Caregivers first noticed symptoms of disorientation, decreased concentration and attention, and disruptions in language experienced by their family members. Approaches to coping with the diagnosis and caring for their relative varied. The author stated that fifteen of the caregivers provided primarily emotional support to their relative, whereas the other five caregivers' responses focused more on the practical needs (i.e., cooking, cleaning, and yard work) of the person with MCI. Fourteen caregivers had sought assistance with legal and financial planning and locating government and community services. All of the caregivers hoped for the possibility of a cure for AD, but were aware of the realities of the disease and sought improved medications to ease the symptoms of the disease.

Pinquart and Sorensen (2002) noted that utilizing available resources (i.e., government assistance, support groups, community programs) alleviates caregiver stress, decreases depression, and minimizes the sense of burden. They found that

ways in which people cope with illness and disability, in general, influenced their feelings of worry and burden. Those individuals who avoided thinking about the future reported the lowest levels of worry and depression. Individuals who had made plans for the future were more satisfied with their choices. Although the use of avoidance as a coping strategy was associated with lower levels of stress, its use was not associated with positive caregiver outcomes such as feelings of contentment and comfort about the future and decisions made. Collectively, these findings suggest that catering to the needs of families will be important as many older adults may face memory impairments in the future.

It is important to understand the issues facing families caring for persons with MCI, as physicians are now able to provide early diagnoses of cognitive decline. Researchers have suggested that planning enables families to cope better and understand the realities of the condition. Studying MCI from a family perspective, specifically within the dyadic relationship of marriage, will assist researchers and clinicians in discerning the issues and challenges that families experience. In order to capture these concerns in a cohesive manner, I analyzed in-depth interviews with spouses of MCI patients to gain insight into the dynamics of marital relationships when challenged by MCI.

### *Theoretical Framework*

Emerson and Cook (1978) posited that exchange of social interactions is the fundamental aspect of human development. Under this premise, people interact with others to benefit from the exchange. The type of relationship depends on the extent to which exchanges take place. There are intrinsic motivations (e.g., innate motives that

drive persons to communicate, personally rewarding or enjoyable to individuals or the relationship) to interact with members of one's relationship network. If the member believes that the interaction will be personally beneficial, then it is more likely that an exchange will take place. By examining beneficial mutual exchanges, the structural components of power within the relationship can be determined. For example, listening to recollections of couples' relationships can reveal some hints as to who had the power in the relationship and who currently has the power in the relationship. The aspect of power may undergo changes as cognitive impairments become more apparent.

Thibaut and Kelley (1986) further expanded the theory to involve exchanges within the dyadic relationship that are interdependent and influence the psychological costs and rewards of the interactions. Costs include feelings of helplessness, conflict and tension, or anxiety. Conversely, rewards include feelings of contentment, pleasure, satisfaction, or happiness. These costs and rewards occur in the context of mutual exchanges that take place within the dyad. They are complex, variable, and may influence the relationships in different ways that distinguish themselves from the dynamics of other relationships. For example, how do the members in a dyadic relationship counterbalance the costs and rewards specific to their situation?

Most of the caregiving literature focuses on the costs of caregiving (e.g., burden), while failing to give attention to the rewards or benefits of caring for a spouse (Kramer, 1997). In addition, caregiving involves mutual exchanges, or reciprocity, between the caregiver and the care recipient. In this context, reciprocity refers to a give and take relationship in which people evaluate their relationship based on perceived equal exchanges between those involved (Goodman, 1985). It serves as a basis for the

development and maintenance of self-esteem, morale, and happiness for older adults (Walker, Pratt, & Oppy, 1992). Dwyer and colleagues (1994) suggested that people provide care to return the exchange of care that was provided to them earlier in life. Although reciprocity is a mutual process, these exchanges are not required to occur at the same point in time and do not necessarily involve giving and receiving the same things. For example, one member of the spousal dyad may need help or care early in the marriage. Later in life, the care receiver may end up providing care for the other spouse as a way to “pay them back.” Raschick and Ingersoll-Dayton (2004) recently proposed the application of social exchange theory for understanding caregiving relationships. Analyses revealed that women, whether wives or daughters, experienced and reported more caregiving costs than men caregivers; however, men did not experience greater rewards than women caregivers. Their use of social exchange theory supports the notion of reciprocity in the relationship. They suggest that the quality of the relationship for the caregiver is influenced by the rewards and costs they experienced.

More specific to marital relationships, Kulik (2001) used social exchange theory to guide the investigation of differences in marital happiness based on the timing of retirement. Couples who retired at the same time expressed more feelings of satisfaction and happiness with their relationship than did couples whose retirement timing was asynchronous. There was less pressure on the spouses when they both were retired, whereas if one spouse worked and the other was retired, there was likely to be more pressure to stay busy and do household work. Findings from this study suggest that asynchronous life events can disrupt marital relationships. Thus, having a

spouse who is experiencing memory loss may be an added stress on the non-memory impaired spouse. How couples respond may be related to the level of impairment and their overall perceptions and beliefs about their relationship.

By examining spousal relationships when one member of the spousal dyad experiences mild cognitive impairment, I gained insights into the costs and benefits of interacting in the relationship and evidence of reciprocal exchanges. Using social exchange theory as my theoretical lens, I examined interactions, intimacy, and household responsibilities in marital relationships and how MCI influences these exchanges. Findings from evidence and theory-based research suggest that aspects of marital relationships in later life are balanced by these mutual exchanges and that the challenge of coping with cognitive impairment is overcome by perceptions of reciprocity (i.e., beliefs about mutuality) within the relationship. I explored how perceptions of intimacy and division of household labor influenced non-memory impaired spouses' perceptions of exchanges within their marital relationship and more specifically, the costs and benefits of those interactions.

### *Purpose of the Study*

Most of the scholarly literature on MCI focuses on the clinical diagnosis and prevalence of the disease. Researchers have given less attention to the psychosocial aspects of MCI and in particular, how couples interact. I searched several databases using terms associated with "MCI". These databases were research-based, focusing on aging-specific research and psychosocial issues across the lifespan. A literature search using *Ageline* yielded 37 citations for the key term of "MCI", but no results were reported when using the combined terms of "marriage" and "MCI" or "family support" and "MCI."

The combined keywords of “family” and “MCI” yielded two results and no results were reported when using the key phrase “social aspects of MCI.” Another combined keyword search of “assistance” and “MCI” found one match. I found none of the above references relevant to the current study, as they consisted of other topics such as computerized memory training and apathy and dysfunction. Using *PsycINFO*, a combined search of “MCI” and “older adults” yielded 39 results. The use of the same key terms stated above yielded the same results. The lack of relevant literature suggests a gap in the research literature and the need to explore the psychosocial aspects of MCI and its influences on spousal relationships. The purpose of this study was to examine the influence of MCI on interactions, intimacy, and household responsibilities within marital relationships.

### *Research Questions*

The aim of this study was to understand the influence of MCI on interactions within marital relationships. Specific research questions addressed how spouses of persons with MCI:

- a. Perceive stability and change in their marital interactions
- b. Describe intimacy within their relationship
- c. Experience division of tasks within the household

### *Definitions*

1. *Mild cognitive impairment (MCI)*: age-related decline in memory and other cognitive processes. MCI is a relatively new diagnosis indicating cognitive changes that do not necessarily interfere with current daily activities or the maintenance of social relationships with others.

2. *Social exchange theory*: exchanges within the dyadic relationship are interdependent and influence the psychological costs and rewards of the exchanges (Thibaut & Kelley, 1986).
3. *Costs*: feelings of helplessness; conflict or tension; anxiety (Thibaut & Kelley, 1986).
4. *Rewards/benefits*: feelings of contentment; pleasure; satisfaction; happiness (Thibaut & Kelley, 1986).
5. *Reciprocity*: give and take relationship, in which people evaluate their relationship based on perceived equal exchanges between those involved (Goodman, 1985).
6. *Socio-emotional Intimacy*: involves a level of perceived companionship, affection, commitment, and emotional closeness (Wright, 1993).
7. *Physical Intimacy*: involves sexual intimacy, including emotional and physical attractions, affectional gestures (Wright, 1993).
8. *Commitment*: level of intimacy and happiness in the marriage; can sustain all other aspects of a marriage in times of conflict and tension (Wright, 1993).
9. *Emotional closeness*: feelings of togetherness and wholeness as experienced by spouses (Townsend & Franks, 1997).
10. *Household responsibilities*: dimensions of domestic labor (i.e., cooking, cleaning, grocery shopping, childrearing, managing finances).

## CHAPTER II

### Review of Literature

Previous research addresses changes and adjustments in the marital relationship when one member of the spousal dyad faces dementia (Wright, 1993); however, most of this research focuses on the burden and negative psychological outcomes (i.e., depression, stress) of providing care to persons with mid- and late-stage dementia. Although there are a few studies of families coping with the early stages of dementia, formally recognizing issues of support and care for persons with mild cognitive impairment represents a new area of study. As memory declines, many spouses take on more responsibility within their relationship. Research on the influence of mild cognitive impairment on the marital relationship will advance understanding of current issues and concerns of spouses providing care and support to their partners.

Although early AD is distinct from MCI, the literature in this area serves as a starting point for understanding the influence of cognitive decline on marital relationships. The following review of literature focuses on issues of spousal caregiving and includes a discussion of how assuming the caregiver role influences perceived levels of intimacy and the division of household labor in the marital relationship.

#### *Spousal Caregiving*

Alzheimer's disease influences various aspects of the marriage including: (a) household responsibilities, (b) intimacy and companionship, and (c) tension and conflict (Wright, 1993). The major themes that are evident throughout the spousal caregiving literature include: (a) caregiver burden and stress, (b) influences of cognitive impairment on the spousal caregiver, and (c) influences of caregiving on the marital relationship.

Because of my interest in spousal caregiving, I direct my attention to the literature involving perceptions of changes in intimacy and division of household tasks when one member of the dyad experiences cognitive declines. Before delving into the literature, I begin by briefly exploring the research on spousal caregiver burden, stress, and depression. This provides insight into the potential personal outcomes of caring for a spouse with cognitive impairment.

### *Spousal Caregiving and Well-Being*

The majority of the literature pertaining to spousal caregiving focuses on individual caregiver outcomes including burden, stress, and depression (Bedard et al., 1997; Majerovitz, 1995; Morris et al., 1988; Wright, 1994). For example, Majerovitz (1995) examined the role of family adaptability as a moderator for psychological adjustment. Findings from standardized interviews with 54 spousal caregivers of persons with varying levels of cognitive impairment suggests that for less adaptable caregivers, longer hours of perceived care were highly related to greater depression. Less adaptable caregivers were individuals who avoided the situation, were rigid in their family role, and were reluctant to change. In addition, greater caregiving stress was also associated with greater likelihood of depression. Similarly, Bedard and colleagues (1997) found caregiver burden positively correlated with frequency of patients' behavior problems. Conducting interviews at two different times, once at baseline and then at a follow-up interview scheduled 1 to 12 months after the initial interview, they found that male caregivers were more likely than female caregivers to report reduced levels of caregiver burden at the follow-up interviews. It is difficult to compare those individuals interviewed one month after the initial interview with persons interviewed twelve months

after the initial interview. The extent and range of the changes in caregiver burden is highly variable and may not be reflected over shorter periods of time.

Morris and colleagues (1988) examined the relationships among intimacy, perceived strain, and depression in spousal caregivers of dementia patients. Caregivers who expressed lower levels of intimacy experienced higher levels of depression and perceived strain in the caregiving role. Those who perceived the loss of intimacy in their marital relationship experienced higher levels of depression, but not strain. The authors suggested that the loss of intimacy placed these caregivers at high risk for developing severe depression and frustration with their caregiving role.

There is an abundance of literature pertaining to caregiver burden (e.g., Clyburn et al., 2000; Goodman, Zarit, & Steiner, 1997; Stuckey & Smith, 1997; Zarit, Reever, & Bach-Peterson, 1980), the majority of which explored predictors and frequency of caregiver burden. Using quantitative methodology, researchers typically examine burden, depression, and stress with various standardized measures (e.g., Zarit Burden Interview, Memory and Behavior Problems Checklist, and Depression Rating Scale). Although this approach provides evidence of the burden of caregiving, it does not always capture the extent to which burden interrupts the caregivers' lives and relationships. The use of qualitative methodologies, either alone or in conjunction with quantitative approaches, is necessary to gain further insight and enhance understanding of the burden in spousal caregiving relationships.

### *Caregiving and Marital Relationships*

Several researchers have explored the similarities and differences of husbands and wives as caregivers (Kramer & Lambert, 1999; Lewis, 1998; Rudd et al., 1999;

Rose-Rego, Strauss, & Smyth, 1998; Wright & Aquillino, 1998). Using place of care (in-home versus institution) as a predictor variable, Rudd and colleagues (1999) investigated how the sex of the caregiver influences spousal and emotional experiences. Family caregivers self-rated their moods and emotional states. Using content analysis, the researchers identified four emotional states: anxiety, anger, guilt, and sadness. Nursing home caregivers experienced greater levels of sadness and guilt than in-home caregivers. In-home caregivers expressed more anger than nursing home caregivers did, with in-home caregiving wives expressing the highest level of anger. Caregiving wives, regardless of place of care, expressed greatest levels of sadness, guilt, and anger.

Researchers frequently report differences in the subjective psychological well-being of husband and wife caregivers of persons with AD. An analysis of several aspects of well-being (e.g., depression, positive and negative affect, life satisfaction) revealed that that caregiving wives reported more negative experiences of psychological well-being than did caregiving husbands (Rose-Rego, Strauss, & Smyth, 1998). The investigators suggested three possible explanations for the negative expressions of caregiving wives: (a) caregiving wives are more emotionally attentive and are more likely to report negative affect; (b) caregiving wives tended to use more emotion-focused coping that is related to higher levels of distress; and (c) caregiving wives generally perform most of the household responsibilities and personal care within the family which creates more stress and as a result, negative expressions occur.

Kramer and Lambert (1999) explored the aspects of household responsibilities, marital relationship, and well-being of husbands who had transitioned into the role of

caring for their wives over a five-year period. Compared to non-caregiving husbands, the authors found that men who had assumed the caregiving role had undergone significant changes in managing their everyday lives. For example, caregiving husbands spent more time on household responsibilities that were traditionally their wives' responsibility. They reported more participation in the religious community but indicated a greater decline in emotional support from family and friends than the non-caregiving husbands did. In addition, caregiving husbands were more likely to report lower levels of marital satisfaction and psychological well-being than non-caregiving husbands.

Wright and Aquilino (1998) used social exchange theory to explore the influences of emotional support exchanges on caregiving wives' perceptions of burden and marital satisfaction. Perceived reciprocity of emotional support in caregiving wives and husbands receiving care was associated with lower levels of caregiver burden and higher levels of marital satisfaction. Husbands' level of impairment influenced the types of exchanges within the relationship, with the number of positive exchanges decreasing as level of impairment increased. Similar results were found for a group of non-caregiving wives; however, the effects were smaller. The authors concluded that positive exchanges between caregiving wives and their husbands were important in achieving an overall sense of well-being and satisfaction in the marriage. As a result, perhaps, these positive exchanges decrease as cognitive impairment increases.

Providing care for a spouse with AD not only influences the well-being of the caregiver, it also disrupts the marital relationship (Lewis, 1998; Navon & Weinblatt, 1996; Townsend & Franks, 1997; Wright, 1993). Wright (1993) identified several aspects of marriage that are likely to change when the spousal dyad is faced with AD,

including changes in household responsibilities and marital roles, changes in intimacy and affection throughout the course of caring, and changes in the levels of tension, conflict, and frustration in the relationship. These factors influence the adaptability of caregivers and the coping strategies that they use to manage everyday life. Caregivers who expressed higher levels of adaptability and who adopted effective coping strategies perceived minimal changes in their marital relationship.

Townsend and Franks (1997) assessed caregivers' subjective perceptions of the quality of care they provided, how satisfied they were with their roles (effectiveness), emotional closeness (perceived intimacy) with the care recipient, and acceptability of their current plans for their family member. Spouses' perceived closeness of the relationship increased their beliefs of the effectiveness of their own caregiving roles. Greater cognitive impairment, but not functional impairment, was related to less emotional closeness between spouses and as a result, they perceive their own caregiving efforts as less effective (1997). The authors concluded that, because members of spousal dyads expected high levels of intimacy and most spousal caregivers experienced high amounts of social isolation, decreased perceptions of emotional closeness were likely to result.

Researchers also have used qualitative methods to explore how caregiving affects the marital relationship. Navon and Weinblatt (1996) examined reasons that people continue to care for their spouse even when institutionalization is an available option. Based on multiple interviews with seven women and three men, they found that caregivers expressed reasons of conscious choice for caring for their spouse at home. These caregivers expressed feelings of wanting to satisfy their family members' needs,

and further described emotions ranging from pity to love. Spousal caregivers, compared to adult children and sibling caregivers, wished to help their partner maintain their identity. The spouses' roles and daily experiences were extremely routine and their time was entirely devoted to caring. These caregivers placed more emphasis on the care recipients' needs than on their own, thereby becoming more socially isolated and losing connections with social and other relational ties.

Similarly, Lewis (1998) explored ways in which dementia challenges couples' marital experiences and relations. Qualitative interviews were conducted with nine spousal carers (three husbands and six wives), ranging in age from 60 to 82. Two of the caregivers cared for a spouse in early dementia; six cared for a spouse with moderate dementia, and one cared for a spouse with late-stage dementia. Eleven major themes emerged from the analyses of the study cases. Three of the themes are particularly relevant to this study. First, in a marriage, intimacy comes naturally and is generally stable throughout the course of the relationship. Although intimacy is a normative expectation within marriage, it does not always exist. All of the persons with dementia had high needs for activities of daily living, and therefore, required their spouse caregivers to help with toileting and bathing. Behavior problems made toileting and bathing more difficult to complete. Having to help with these activities of daily living had a negative effect on intimacy for some spouses. They reported that having to provide personal care in conjunction with the changing personalities of their spouses intensified frustration levels and increased depression. Furthermore, they felt that this person was no longer the partner of their shared history. Lack of perceived intimacy influences the

ways in which caregivers express feelings of satisfaction and contentment in their current relationship.

The second theme suggests older husbands respond to caregiving within the context of their traditional breadwinning roles. This implies that household responsibilities influence the marital relationship. Lewis (1998) reported that husbands view the caregiving role as task-centered. Men focus on the task and concentrate time and energy into this role without much emotion or nurturing involved. This is not to say that men do not care about their wives, but that their view on caregiving is much different from that of women. Rather than being task-centered, wives see the caregiving role as one in which they nurture and provide care for the other person. Household roles, including traditional gender roles, play an important part in how spouses perceive the relationship in which they are involved.

The third theme, reciprocity in relationships, demonstrates the application of social exchange theory. The caregivers believed they were obligated to pay back their spouse for care throughout their lives together. According to social exchange theory, people evaluate their roles and exchanges in order to adapt to the situation. The context of the situation serves as the basis for how individuals perceive the world around them. Depending on how they perceived their past and current situation, caregivers evaluated their sense of reciprocity and either devalued themselves, devalued their partners, or believed that they were reciprocating their spouses' care provided earlier in the life course. The caregivers based their beliefs on normative perceptions of marriage and perceptions of their own roles as a husband or wife caring for a spouse with dementia. Caregiving requires the constant assessment and reassessment of roles in the context

of the entire life experience of the spouses (Lewis, 1998); thus, interactions throughout the couples' relationship shape their perceptions and beliefs about their caregiving roles.

Overall, the research on caregiving and marital relationships suggests differences in the ways in which husbands and wives respond to their caregiving roles and responsibilities. Burden, stress, and depression are common outcomes for spousal caregivers, with wives who provide care typically reporting higher levels of psychological distress than husbands. The dynamics of marital relationships also change as one spouse assumes more responsibility for the care of the other.

### *Intimacy and Caregiving*

Intimacy in caregiving represents a level of companionship, affection, commitment, and emotional closeness as perceived by spouses of persons with cognitive impairment (Allen et al., 1999; Townsend & Franks, 1997; Wright, 1993). Wright (1993) explored marriage through intimate accounts of couples dealing with AD. She suggested that marriage is bound by companionship; people need this type of relationship. Interactions are essential to everyday living. When one spouse experiences memory problems, interactions and exchanges within the marital relationship often change and may become asynchronous. The asynchronous nature of the relationship influences the perceived level of reciprocity felt by each of the members of the spousal dyad. Spouses with memory loss may experience social isolation because they have difficulty effectively interacting with their partners. Wright described couples who deal with cognitive impairment as living together, although in different

worlds. The caregivers adapt by accepting their new roles and compensating for things otherwise lost.

A second aspect of intimacy in caregiving that Wright (1993) discussed was affection within the marital relationship. With increasing age, biological, social, and psychological factors can influence intimacy. Wright equated affection with sexual intimacy and concluded that spouses often exaggerate frequency of sexual contact possibly due to embarrassment, wishful thinking, and a longing need for closeness. Exploring sexual intimacy helps researchers to understand the social aspect of the marital relationship that may undergo the greatest change when one spouse has cognitive impairment. It is, however, difficult to assess because older people are reluctant to discuss intimate matters with others (1993).

A third aspect of intimacy in caregiving is commitment in the relationship (Wright, 1993). Although not a direct form of intimacy, commitment depends on intimacy and happiness in the marriage. Commitment is the one aspect of marriage that can sustain all others in times of conflict and tension. As people age, their commitment to one another may grow stronger and deeper as they become confident in their commitment for the future. However, when caregivers' health begins to decline, commitment also may decline (Wright, 1993). The caregiver wonders: 'who will take care of her or him?' When this happens, reevaluation of their roles and their marital relationship is important. Relationships are complex and variable; thus, the previous statements are limited because they represent an overgeneralization that may not hold true in all cases (Blieszner & Shifflett, 1990).

Townsend and Franks (1997) suggested an additional aspect of intimacy, emotional closeness. Emotional closeness involves feelings of togetherness and wholeness as experienced by spouses who care for persons with cognitive impairment. Examining the experiences of spouses caring for persons with cognitive or functional impairments, the authors concluded that emotional closeness was the basis for establishing an intimate relationship. Greater levels of cognitive impairment lead to lower levels of perceived emotional closeness by spousal caregivers. This is particularly due to the high amounts of social isolation that spousal caregivers often face. Emotional closeness provides safety and understanding as every dyadic relationship goes through the life stages.

Another unique aspect of emotional closeness involves examining the unequal representation of husbands and wives as spousal caregivers (Allen et al., 1999). Allen and colleagues (1999) hypothesized that unequal representation is a function of two reasons: (a) traditional gender-role norms, and (b) emotional closeness within the marital relationship. Their sample included married men and women with advanced stage cancer who had appeared to need a caregiver. They found that gender was a highly significant predictor of caregiver nomination, with wives one-third more likely than husbands to nominate their husbands as their primary caregiver. Intimacy played an important role in this nomination in that respondents who reported that their spouse was their confidant also nominated them as the primary caregiver. Although they had expected emotional closeness to be more important for wives in the nomination of their spouse as primary caregiver than for husbands, this was not evident. The authors suggested that researchers should focus on the details of the link between instrumental

and expressive support among spouses, as well as the gendered aspects of caregiving and care receiving.

Simson and colleagues (1989), through an analysis of intimacy attributes, explored the nature of interpersonal intimacy. They captured the caregivers' perceptions of intimacy through a retrospective examination of the relationship prior to onset of cognitive impairment and during mild, moderate, and severe dementia. Although perceived intimacy had declined as the level of dementia increased, spouses' ratings of emotional attributes such as "likes you" and "knows you well" increased. Conversely, spouses' ratings of behavioral attributes such as "has similar interests" and "provides sexual satisfaction" were lower. To develop and maintain interpersonal intimacy, the authors suggested that interventions occurring soon after the diagnosis may benefit both caregivers and care receivers.

One critique of the intimacy and caregiving literature is that researchers use different terminology when referring to matters of intimacy. How they define intimacy depends on the caregiving situation and the context in which it is used, and varies across relationships. In addition, researchers use various measures to assess the importance and meaning of intimacy in caregiving relationships (Townsend & Franks, 1997; Wright, 1993). As a result, it is difficult to generalize the findings across studies. Because intimacy has a high personal meaning and interpretation varies, qualitative methodologies provide an opportunity to better capture the meaning and perceptions of intimacy within caregiving relationships.

### *Division of Household Responsibilities*

A review of the literature presented from 1989 to 1999 by Coltrane (2000) provides insight into the gender construction and theoretical ideologies underlying household labor. Household responsibilities involve dimensions of domestic labor (i.e. cooking, cleaning, grocery shopping, childrearing, handling finances). Coltrane ascertained that employed women are doing less housework than before and that husbands are doing somewhat more housework. However, women still do at least twice as much routine household labor as men. The question of who does what in the relationship, however, is still unanswered due to the variability in family structure and marital relationships.

Coltrane (2000) also noted theoretical advancements made in understanding the division of household labor. He suggested three explanations of the division of household responsibilities. The first suggested that the person who makes the most money will do less housework. The second proposed that gender-constructed attitudes and beliefs increased the likelihood of conformity to gender-based division of labor. Finally, employment superseded the amount of time spent on housework or household responsibilities. These assumptions about household labor help to lay the foundation for the reasons of responsibility allocations.

Landmark studies (e.g., Bernard, 1972; Blood & Wolfe, 1960; Oakley, 1974; Vanek, 1974), as well as review articles (e.g., Coltrane, 2000; Kamo, 2000; Osmond & Thorne, 1993; Shelton & John, 1996; Thompson & Walker, 1989) on division of household labor focus on younger and middle-aged couples. Findings from these studies and reviews suggest that while husbands continue to do less housework than

wives, their contributions are increasing at a slow pace. Variables such as family size, age of the couples, life stage, ethnicity, and the presence and contribution of children affect the allocation of labor within a household.

Research examining division of labor (i.e., the perceived amount of time spent on domestic work by husbands and wives) between older couples is limited (Pina & Bengtson, 1995). A search of the family gerontology literature yielded three studies published in the years 1994, 1995, and 2001. Stoller (1994) used feminist perspectives to illustrate the experience of caring for frail elderly family members in the context of teaching students about gender-specific roles in caregiving. Men and women differ, not only in the likelihood of providing care, but also in the experience of caregiving itself. She suggested that the division of labor focuses on traditional tasks performed by men and women and that these tasks subsequently influence their caregiving performance.

In 1995, Pina and Bengtson studied retired women who spoke of their household responsibilities in terms of support by husbands, marital happiness, and gender ideologies. The authors note that people place symbolic meaning on tasks deemed appropriate for their sex. Perceptions of spousal support mediated the relationship between division of labor and wife's psychological well-being. Wives reported less spousal support when division of labor was not equal between them and their husbands, which, in turn, leads to lower levels of marital satisfaction and happiness. They concluded that ways in which division of labor influences wives differs for those previously employed compared to long-term homemakers.

In a review involving the influences of men's and women's retirement on subjective well-being, Kim and Moen (2001) found three factors associated with

subjective well-being: (a) economic resources, (b) social relationships, and (c) personal resources. Although gender is a key factor in the experience of retirement, this study did not examine the sex differences in well-being. The authors suggested that using a life course and ecological approach captures the retirement transition through personal life histories and ecological contexts. Psychological adaptation processes were important to maintaining and increasing an overall sense of well-being. However, division of household labor predicted well-being in retirement. Relationships where couples identified their household tasks and completed their prescriptive responsibilities resulted in higher levels of psychological well-being for both husbands and wives.

Wright (1993) examined division of household labor in marital relationships in which one member had cognitive impairments. Conflicts that arise from household tasks are due to caregiver expectations about their roles as well as their spouses' roles in the home and to changes in lifestyle and money management. Because of the affliction of AD on their partner, spousal caregivers took on a more worried and protective manner when dealing with matters of money. According to Wright (1993), timing of events in later life is a major determinant of development and how people perceive their social relationships with others. Couples who experience asynchronous timing of life events are more likely to experience conflict associated with the burden of household labor than those couples who experience synchronous timing of events in later life. Due to assuming extra responsibilities through the asynchronous timing of events, caregivers often perceive their relationships as conflicted. Caregivers need to look beyond the scope of household responsibilities in order to examine the overall quality of their relationship with their spouse.

The literature on older adults and the division of household labor does not provide a clear depiction of the diversity and variability of marital relationships. Most of the research in this area is focused on younger and middle-aged married couples (Coltrane, 2000). Pina and Bengston (1995) interviewed retired women and suggested that people evaluate their roles according to the support they receive from their spouse, marital happiness, and gender expectations. Role evaluation is a common occurrence throughout the life-span (Coltrane, 2000). In considering household responsibilities in relationships where one spouse has cognitive impairments, we are able to gain a deeper understanding of the social, emotional, and psychological influences on the spousal caregiver. This aspect of marriage is highly indicative of the core tenets of social exchange theory. The theoretical framework will guide the exploration of the reciprocal exchanges of the responsibilities between the spouses.

### Conclusion

Spousal caregiving research provides insight into the influence of moderate to severe memory loss on individual well-being and marital relationships. Research involving husbands and wives as caregivers suggests differences in the ways in which they approach caregiving, as well as the ways in which the caregiving role influences their lives (Kramer & Lambert, 1999; Rose-Rego et al., 1998; Wright & Aquilino, 1998). The spousal caregiving literature represents a broad depiction of the experiences of spouses who provide care for their partners.

There are several limitations in the literature on spousal caregiving and memory loss. First, research typically has not addressed psychosocial aspects of mild memory loss and how these aspects influence relationships. Because MCI is a relatively new

diagnosis, researchers and clinicians are still trying to understand the progression of the condition (Petersen et al., 1999); few are focusing on relationship outcomes (Garand, 2004; Garand, Dew, & Reynolds, 2004).

As shown in Table 1, the studies reviewed for this proposal used diverse methodologies and descriptions of the cognitively impaired samples. Researchers do not clearly define their sample with respect to cognitive impairments. Study samples consist of participants with varying levels of cognitive impairment and do not compare outcomes by impairment levels, which limit the generalizability of the findings (Barber, 1993; Lewis, 1998; Majerovitz, 1995; Morris, Morris, & Britton, 1988; Townsend & Franks, 1997). For example, burden, stress, and depression are related to caring for an individual with cognitive impairments; however, the extent of the impairment will increase the likelihood of those outcomes.

Table 1

*Overview of Caregiving and Cognitive Impairments Literature*

<i>Authors</i>	<i>Year</i>	<i>Methods</i>	<i>Stage of Cognitive Impairment</i>
Barber	1993	Quantitative	Various (not specified)
Bedard, Molloy, Pedlar, Lever, & Stones	1997	Quantitative (pre and post)	Mild to moderate
Cummings	1996	Qualitative	Mild
Dura, Haywood-Niler, & Kiecolt-Glaser	1990	Quantitative	Senile dementia
Garwick, Detzner, & Boss	1994	Qualitative	Mild to moderate
Kramer	1997	Quantitative	Mild to moderate
Kuhn	1998	Qualitative	Mild
Lewis	1998	Qualitative	Various (not specified)
Majerovitz	1995	Qualitative	Various (not specified)
Morris, Morris, & Britton	1988	Quantitative	Various (not specified)
Rudd, Viney, & Preston	1999	Quantitative	Mild to moderate
Townsend & Franks	1997	Quantitative	Various (not specified)
Wright	1993	Quantitative	Alzheimer's disease
Wright	1994	Quantitative	Alzheimer's disease

There is also a strong reliance on quantitative methodologies in examining spousal relationships and the influences of caring for persons with memory impairments. Using self-report measures can result in a response bias, where participants report what they perceive to be a socially desirable answer (Kamo, 2000). This can create problems in over- or under-reporting of phenomena that occur in late-life marriages. Findings from the few studies that used in-depth interviewing techniques provide a deeper understanding of the dynamics of the relationship, and insights as to why spouses assume the caregiving responsibility even when institutionalization is an available alternative. Some aspects of relationships require special attention through face-to-face interviews to appreciate the diversity of spousal relationships. By focusing on specific aspects of marital relationships (i.e., intimacy and division of household labor) and using the guidance of theory, I explored the influences that mild cognitive impairments have on marital relationships.

## CHAPTER III

### Methodology

The purpose of this study was to examine the influence of MCI on intimacy, interactions, and household responsibilities within marital relationships. To address the research questions, I analyzed in-depth qualitative interviews through a case study approach. This study was based on secondary data analysis of data that were gathered to assess the issues, concerns, and support needs of families with MCI. In this chapter, I discuss: (a) the original research study, (b) the use of secondary data, and (c) a description of the sample and data collection procedures and analysis plan.

#### *The Original Research Study*

With support from the Alzheimer's Association (Project # IIRG-03-5926) data collection for the study, "*Caregivers of Persons with Mild Cognitive Impairment: Information and Support Needs*" began in November 2003. The Principal Investigators of the study are Drs. Karen A. Roberto and Rosemary Blieszner. Dr. Karen L. Wilcox serves as the Project Coordinator and I am the graduate research assistant. The primary aim of this study is to develop a set of items that will serve as key indicators of information and support needs of families caring for persons with MCI. This short-term longitudinal study (2004-2006) consists of three phases: (1) initial interviews with the person with MCI, the primary family member, and the secondary family member, (2) six-month follow-up interview with the primary family member, and (3) one-year follow-up interviews with both the primary and secondary family member.

In collaboration with memory clinics located in southwest Virginia, our goal is to identify 100 individuals with MCI. The clinics use a battery of tests to determine the

presence of MCI including: (a) MMSE (score of 24 or higher), (b) activities of daily living (ADLs) (i.e., toileting, bathing, dressing), and (c) instrumental activities of daily living (IADLs) (i.e., managing a checkbook, cleaning, cooking). Once persons with MCI (referred to as “elders” throughout the remainder of this document) agreed to participate in the study, we conducted brief interviews with them and longer, more in-depth interviews with their primary family members (e.g., spouse, partner, or adult child). In addition, the primary family member completed a series of self-report standard measures.

Interviews typically took place in the participants’ homes. The elders and the primary family members were interviewed separately. Interview questions for the elder focused on long-term care options (e.g., family care, reliance on friends) and other future care-related decisions (i.e., relocating to an assisted living facility or other housing options). Interview questions for the primary family members focused on managing everyday life, ways in which they cope, anticipations for the future, and how the family will manage future changes and any future planning techniques already decided upon or discussed. At the end of the interview, primary family members suggested the name of another family member who sees or talks to the person with MCI at least monthly. We refer to this person as a secondary family member (e.g., adult child, sibling, or friend). Interviews address issues similar to those discussed with the primary family member; however, the view is from the perspective of a more distal supporter.

## *Secondary Data Analysis*

Secondary information consists of data collected and documented by others that is available for use in future research studies. This information presents efficient and inexpensive answers to subsequent questions posed from primary research. Stewart and Kamins (1993) suggested that there are advantages and disadvantages to using secondary data. For this study, the benefits and advantages to using secondary data cases outweigh the disadvantages.

In general, the advantages of using this information include: (a) a time and cost effective technique, (b) a useful way to pose new research questions from a broad research study, and (c) a means for determining the generalizability of the data found to the larger population (Stewart & Kamins, 1993). The first two advantages that were discussed by Stewart & Kamins (1993) apply to this study. However, the third advantage is not relevant; this study examines marital relationships in which one member of the spousal dyad has memory difficulties and does not generalize to the larger population. An additional advantage to using this dataset is that I have had the opportunity to be involved with the primary project from its early stages and have been responsible for interviewing the secondary family members. I am interested in how family members work together when challenged by cognitive impairments and how this might or might not influence their relationships. My sample and analysis plan reflect data collected by the project coordinator. Given my research interests and involvement with the study, analyzing the data specific to spousal interactions provided insight into the early stages of memory impairments and the issues and concerns facing the couples. It also provided preliminary findings relevant to the original research study.

Although secondary data is convenient, it does have its limitations. In general, disadvantages include: (a) potential problems in the data collection, analysis, and interpretation, and (b) data may be so extensive that they allow many different conclusions (Stewart & Kamins, 1993). These disadvantages do not apply to this study because I was involved in all stages of the project's development. However, the research team developed the interview questions prior to my involvement with the study. Although the initial interview questions globally addressed questions related to their relationships, they were not framed specifically to spousal interactions. I had the opportunity to provide input for the six-month follow-up interviews with the spouses, which resulted in the addition of several questions that focused specifically on the couples' relationship.

## Study Methodology

### *Sample*

Prior to the start of data collection, the Virginia Tech Institutional Review Board (IRB) reviewed and approved this research (see Appendix A). As of February 2005, the primary sample consisted of 43 families; 20 involved spouses or partners as the primary family member (13 females and 7 males). The initial criteria used to select the study sample were: (a) interviews completed by February 2005, and (b) equal representation of male and female spouses. Following the sample criterion, 5 female and 5 male primary family members were randomly selected using a random numbers table (Howell, 2001). Because of incomplete data, interviews from only 5 male primary family members were available; thus, all 5 were included in this study.

Table 1 provides specific demographic information for elder-primary family member dyad. I used pseudonyms for each participant throughout this study to protect the confidentiality and identity of all participants. Elders ranged in age from 66 to 86 years ( $M= 78.6$ ;  $SD= 6.64$ ). Primary family members ranged in age from 65 to 89 years ( $M= 76.6$ ;  $SD= 8.30$ ). The number of years the couples were married ranged from 34 to 62 ( $M= 53.0$ ;  $SD= 8.31$ ). Two of the primary family members had a high school education; three had completed some college or trade school; one was a college graduate, and two had completed their graduate school degree. Two primary family members did not complete any of the standardized forms for the interview. See Table 2 for individual participant demographic information.

Table 2

*Participant Demographics*

<i>Couple</i>		<i>Years Married</i>	<i>Age</i>		<i>Primary's Education Level</i>	<i>Household Income Level (per year)</i>
<i>Elder</i>	<i>Primary</i>		<i>Elder</i>	<i>Primary</i>		
Clara	Cliff	62	86	83	Graduate degree	\$48,000-\$83,999
Dena	David <sup>a</sup>	58	77	-----	-----	-----
Joy	John <sup>a</sup>	53	-----	-----	-----	-----
Lucy	Len	61	86	89	Graduate degree	-----
Thelma	Tom	34	85	83	Bachelor's degree	\$48,000-\$83,999
Harold	Helen	48	76	69	1-3 years of college	\$120,000 +
Jack	Jean	54	74	72	Trade school	\$12,000-\$23,999
Mike	Mary	55	76	72	1-3 years of college	\$48,000-\$83,999
Orrin	Olivia	58	81	80	High school or GED	\$24,000-\$47,999
Walter	Wendy	47	66	65	High school or GED	\$48,000-\$83,999

<sup>a</sup> Did not complete the background demographic sheet.

*Measures*

The data used for this study came from interviews with the primary family member; thus, they represent the non-impaired spouse's perspective of the influence of memory loss on the marital relationship. Sociodemographic variables including age, education, income, number of years married and number of marriages were used to describe the sample (see Appendix B). Open-ended interview questions that focused on issues specific to the marital relationship addressed: (a) activities participated in as a

couple, (b) how much time spent together, (c) division of household responsibilities, (d) how they show care or affection towards one another, and (e) how they manage everyday life (see Appendices C and D). We framed the questions to assess stability and change in the marital relationship since the onset of memory problems. For example, participants were asked about each aspect of their marital relationship with respect to whether anything has changed and if so, how. All interviews were tape-recorded, transcribed, and verified (by re-checking the tape-transcription correspondence).

In addition to participating in the semi-structured interviews, the primary family members completed a series of standardized instruments. Scores from three of those measures were used in this study (see Table 3). Their responses to these measures provided information about the memory and behavioral changes of the elders as they related to the outcomes for and responses of the primary family members. The *Revised Memory & Behavior Problems Checklist* (RMBPC: Teri et al., 1992) is a 24-item scale in which the spouse rates the occurrence and severity (1= *a little*; 2= *moderately*; 3= *very much*; 4= *extremely*) of a series of problematic behaviors that the person with MCI is likely to exhibit (see Appendix E). Severity indicates how bothered the primary family members are by the exhibited behavior. Reported alpha coefficients ranged from .67 to .90 and satisfactory validity has been established. For the present study, the alpha coefficient was .80. Common memory and behavior problems exhibited by the elder included: (a) asking the same question over and over, (b) trouble remembering recent and past events, (c) losing or misplacing things, (d) forgetting what day it is, (e) difficulty concentrating on tasks, and (f) appearing anxious or worried. The total number of

memory and behavior problems was calculated by summing the items. Severity of the memory and behavior problems was determined by multiplying the total number of memory and behavior problems by the average bothersome score. The frequencies of common behaviors are shown in Table 4.

The short form of the *Zarit Burden Interview* (Bedard et al., 2001) assessed the extent to which the spouses or partners felt burdened by their role and relationship with the person with MCI (see Appendix F). Scores range from 0 to 48, with higher scores indicating greater burden. This 12-item measure yielded a reliability coefficient of .88, which is comparable to that of the full version of the scale (.83 to .91) (Zarit et al., 1987). For this study, the alpha coefficient was .91.

The *Center for Epidemiological Studies-Depression Scale* (CESD: Radloff & Teri, 1986) was used to identify evidence of depressive symptoms of the spouse (see Appendix G). For ease of administration, the yes-no response format was used (Blazer, Burchett, Service, & George, 1991). Scores range from 0 to 20 with higher scores signified greater levels of depression; a cut-off of 9 indicated depression. When used to assess depression in community-dwelling older adults, reliability coefficients ranged from .85 to .91. For the current study, the alpha coefficient was .76.

Table 3

*Participant Scores on Standardized Measures*

<i>Couple</i>					
<i>Elder</i>	<i>Primary</i>	<i>Memory/Behavior Problems (N)</i>	<i>Problems Bothersome (M)</i>	<i>Burden</i>	<i>Depression</i>
Clara	Cliff	5	0.00	3	4
Dena	David <sup>a</sup>	-----	-----	-----	-----
Joy	John <sup>a</sup>	-----	-----	-----	-----
Lucy	Len	6	0.96	5	4
Thelma	Tom	3	6.00	0	7
Harold	Helen	13	10.01	16	5
Jack	Jean	15	30.00	25	5
Mike	Mary	5	2.00	8	4
Orrin	Olivia	9	12.24	10	8
Walter	Wendy	5	5.00	2	4

<sup>a</sup> Did not complete the standardized scales.

Table 4

*Frequencies of Memory/Behavior Problems*

<i>Memory/Behavior Problem</i>	<i>Frequency</i>	
	<i>Husbands</i>	<i>Wives</i>
Asks the same question over and over	2	5
Trouble remembering recent events	3	5
Trouble remembering past events	2	4
Loses or misplaces things	3	3
Forgets what day it is	2	3
Starts, but does not finish things	1	2
Difficulty concentrating on a task	1	3
Destroys property	0	1
Wakes you or other family members at night	0	1
Talks loudly and rapidly	0	3
Appears anxious or worried	0	3
Engages in potentially dangerous behavior	2	1
Verbally aggressive to others	0	2
Appears sad or depressed	0	3
Expresses feelings of hopelessness	0	3
Crying and tearfulness	0	2
Comments about death of self or others	1	0
Talks about feeling lonely	1	0
Comments about feeling worthless	0	1
Comments about feeling like a failure	0	1
Arguing, irritability, and/or complaining	0	3

*Data Coding and Analysis*

Following multiple readings of the transcripts, I utilized an open coding process through which a list of themes and patterns emerged. Following several meetings with Dr. Roberto, the coding scheme underwent four iterations before reaching consensus. We reached 100% agreement for five major coding categories: dynamics of the relationship, relationship outcomes, socio-emotional intimacy, physical intimacy, and division of household responsibilities. Social exchange theory provided a conceptual framework for linking participants' responses to the research literature and for keeping the focus of the data coding and analysis specific to the purpose of this study and

allowed me to ignore relevant data (Yin, 1989). In addition, social exchange theory is embedded into the coding scheme and was kept up front as the coding scheme emerged and was developed. See Table 5 for the coding scheme. This coding scheme was applied to each case individually.

Table 5

*Coding Scheme*

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**100. DYNAMICS OF THE RELATIONSHIP**

- 101. Self-disclosure
- 102. Decision-making
- 103. Communication style
- 104. Individual differences (i.e., how spouses perceived their roles in the relationship)
- 105. Primary as initiator (i.e., influences the structure of interactions/activities)
- 106. Couplehood (i.e., “we” language)
- 107. Power/control (i.e., expression of differential behaviors/interactions)
- 108. Shared/joint activities

**200. RELATIONSHIP OUTCOMES**

- 201. Conflict and tension
- 202. Negative emotions (e.g., helplessness, frustration, stress, sadness, worry)
- 203. Positive emotions (e.g., pleasure, happiness, contentment)

**300. SOCIO-EMOTIONAL INTIMACY**

- 301. Companionship
  - 302. Affection (e.g., verbal displays of affection)
  - 303. Closeness
-

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304. Support

305. Concern

**400. PHYSICAL INTIMACY**

401. Sexual intimacy

402. Affectional displays (e.g., hug, kiss)

**500. DIVISION OF HOUSEHOLD RESPONSIBILITIES**

501. External help (e.g., maid/housekeeper)

502. Equal division and responsibility

503. Primary assumes greater responsibility

504. Elder assumes greater responsibility

505. No changes

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*Trustworthiness*

Adapted from Anafara and colleagues (2002), Table 6 demonstrates the assessment strategies used to ensure the quality of this research. To achieve credibility, I employed strategic investigator triangulation, through which others provided feedback on coding, as well as on the coding scheme. The interviewer completed member checks with each interviewee throughout the process as a form of credibility. Transferability was achieved through purposive sampling, in which participants were selected for participation in this study if they were married and were dealing with memory loss. Thick description of the individual couples' cases were provided through case summaries followed by a further cross-case analysis. Dependability was accomplished by employing the code-recode strategy. Each transcript was coded every time that the

coding scheme was revised for a total of five coding revisions. Triangulation and peer examination of the coding scheme and transcripts also demonstrated the dependability of the current research study. To demonstrate confirmability in this study, triangulation was employed once again. Data source (i.e., concordance with previous literature) and investigator triangulation supported the confirmability aspect of trustworthiness.

Furthermore, my goal in conducting and analyzing this research was to recognize any biases that I had throughout the research process. I kept a journal consisting of my thoughts and ideas that emerged during the process of the coding and analyzing the data for the project. The journal primarily consisted of ideas that contributed to the development of the coding scheme. I was aware of my own research biases, interests, and preconceptions throughout the extent of this qualitative case study analysis.

Table 6

*Assessment of Research Quality and Rigor*

<i>Qualitative Term</i>	<i>Quantitative Term</i>	<i>Strategy employed</i>
Credibility	Internal validity	<ul style="list-style-type: none"> <li>• Investigator triangulation</li> <li>• Member checks</li> </ul>
Transferability	External validity	<ul style="list-style-type: none"> <li>• Purposive sampling</li> <li>• Thick description</li> </ul>
Dependability	Reliability	<ul style="list-style-type: none"> <li>• Code-recode strategy</li> <li>• Triangulation</li> <li>• Peer examination</li> </ul>
Confirmability	Objectivity	<ul style="list-style-type: none"> <li>• Triangulation (data source and investigator)</li> <li>• Reflexivity (i.e., recognizing biases of the researcher)</li> </ul>

## CHAPTER IV

### Results

In the first part of this chapter I introduce the ten couples selected for this study and present a brief synopsis of their relationship. Then I present the overall study findings, prepared as a manuscript prepared to be submitted to a peer-reviewed scholarly journal.

#### Case Summaries

The following are summaries of each of the cases, including a synopsis of the couples' relationship. Each couples' story about MCI is distinct, yet similar to the other couples; thus demonstrating the complexity of marital relationships.

##### *Case 1. Clara and Cliff*

A couple of years ago, Cliff noticed that Clara's memory was starting to decline. Following a recommendation from their family doctor, Cliff took Clara to the memory clinic to be tested. Cliff recalls telling the clinic that his memory is just as poor as Clara's; however, the neurologists did not concur. Cliff worries about the future; "it would be awful hard on me for her to need assisted living because I don't want her to leave me." If needed, he has no problem doing more around the house. They have a woman who cleans their home one-half a day once a week. Since Clara's memory problems began, Cliff has taken over a lot of the cooking. He enjoys cooking very much and does not perceive this added responsibility as burdensome or problematic. Together, Cliff and Clara participate in church-related functions; however, Cliff stated that they never have been the type of couple to do many joint activities. When referring to changes in their marital relationship, Cliff stated "if there is any difference, it is better."

Relationship Synopsis: When discussing relationship matters, Cliff's responses suggested that he is concerned about the influence that Clara's memory difficulties has on their marital relationship rather than on him as an individual. For example, Cliff is worried about her future and cannot imagine a life without Clara. This further demonstrates Cliff's commitment to Clara within their marriage. In addition, Cliff believes that their marital relationship is getting better indicating strong couple cohesion. It is not clear what he believes is responsible for improving their relationship. He is supportive of Clara. He is by her side at all doctor visits and has taken over many of the household responsibilities.

#### *Case 2. Dena and David*

About 14 years ago, David and Dena experienced a major lifestyle change; they lost all of their money. They have gone from having maids and chauffeurs to having to be responsible for their own daily needs. David first noticed changes in Dena about four years ago. She was emotional and forgetful; behaviors she was very unlikely to exhibit in the past. Dena enjoys staying up late and sleeps until mid-morning. David believes that she would stay in bed all day if she could. David used to wake Dena up in the morning and supervise her taking her pill four to five times a day. Dena would call David at work and he would have to leave to tend to her needs, which caused him some frustration. He decided to hire a maid to wake Dena, help get her dressed, and make her breakfast. David refuses to allow Dena to drive, which she strongly resents. David feels helpless, but believes it is something that had to be done, whether she likes it or not. David also has noticed that gradually, Dena has had fewer friends. He attributes this loss to her personality and her peculiarities (e.g., always being late). Physically

Dena does nothing besides make the bed and maintain personal hygiene. Dena has never been accustomed to domestic responsibilities and routines. David stated that Dena imagines that she did things that she never has. For example, Dena told David about how she cooked for him, but David says that he “does not know where he was” when that was going on. When asked how long they had been married, David replied “58 miserable years...she wants to do what she wants to do when she wants to do it.”

Relationship Synopsis: The lifestyle change that this couple encountered has had a significant influence on their marital relationship, perhaps more than Dena’s memory and behavioral changes. Being responsible for waking Dena and making sure she took her medications was very stressful for David, primarily because it interfered with his ability to work. He hired a maid to take over these responsibilities. Dena has gradually lost friends, which has reduced the potential of informal support for the couple. David and Dena have been married for 58 years, although from David’s comments, it appears to have been a difficult relationship throughout its history. Their marital relationship is bound by conflict and tension, as well as other negative emotions (i.e., frustration, stress). This case sheds light on the fact that other factors besides memory impairment may influence spouses’ perceptions of the marital relationship.

### *Case 3. Joy and John*

In 1999, John was away at a rehabilitation center for the blind. When he returned home for a long holiday weekend, he noticed changes in Joy’s memory. John recalled that short-term memory difficulties, such as forgetfulness and a lack of concentration, were evident. Together they decided that Joy should be tested for memory loss. John stated that “there are multi-problems associated with old age and we need to find out

about them.” They have a maid to clean their house and have always had this type of paid assistance. John believes that his health problems and late-onset blindness has put a strain on Joy, stating, “She is more or less confined, for what she needs to do for me.” They have talked about the possibility of John attending an adult day care center once a week. He said that “It seems as though she is tired out with me.” John believes that he is causing stress for Joy, which also causes him some stress. Along with memory difficulties, Joy has arthritis and breathing problems. John worries that caring for him is too much for her to take. Joy has assumed greater household responsibility (i.e., driving, cooking, grocery shopping). In addition, John has taught Joy how to manage the household finances as he used to do. He states, “It is a chore for her...but it is one of those necessary things.”

Relationship Synopsis: John is supportive of Joy’s contributions to the household and appreciates the care and support that she provides to him. He believes that she is doing very well in managing daily household responsibilities and personal activities. Unlike the other couples in this study, the elder is assuming greater household responsibility than the spouse. John’s health issues are the major cause of the individual role shifts in this family. This places more strain on both members of the spousal dyad. They are fortunate to have a strong and supportive family network. Although John states that his abrupt blindness and health problems have required him to take an entire new view of life, he remains supportive of his wife’s effort to uphold things that need to be done.

#### *Case 4. Len and Lucy*

In 2002, Len and Lucy made the difficult decision to move from their home in San Diego to southwest Virginia to be closer to family. Len suggested that they made the decision, in part, because of the health and memory problems that Lucy was experiencing, "You can't always count on friends for assistance." For Len, caregiving is more of a family issue. After moving, their daughter suggested they visit a memory clinic. Len thought that it was a good idea because he had noticed signs of confusion and symptoms of depression in his wife's mannerisms. The neurologists at the memory clinic advised him not to worry, but Len cannot help worrying that Lucy's memory problems are an indication that she is developing Alzheimer's disease. He is concerned about Lucy's memory lapses and stated that her memory seems to be much worse when she is tired. Although Len stated that Lucy has always been stubborn, she appears to be getting more so. He expressed growing frustration because she is resistant to suggestions that he makes, which is quite upsetting to him. Len and Lucy are life-long companions. They spend a lot of time together, but also enjoy individual activities with friends. They registered for volunteer work at a local library; however, Lucy had a falling accident that prohibited her from volunteering. Len decided that because Lucy was unable to volunteer, he also would not partake in the volunteering activity. Because they live in a full-service retirement home, Len and Lucy do not have any major household responsibilities besides making the bed. Although it is "horrible" for Len to think about the future, he hopes that Lucy will not decline too much, but if she does, he has decided to place her in an assisted living facility or a nursing home.

Relationship Synopsis: This couple exhibits a strong sense of “couplehood” as indicated by Len’s consistent use of the word “we,” rather than “I” throughout the interview. Len rarely referred to either Lucy or himself as separate individuals. They have open communication with one another and revealed no signs of power or control issues within their relationship. Significant issues or situations appear to be discussed and decided upon by both members of the spousal dyad. Lucy’s memory problems led to their relocation, but have not changed their marital relationship. Len continues to speak highly of their marriage and expressed strong emotional commitment to their relationship. Changes in the division of household responsibilities have occurred because of their housing situation and not particularly because of Lucy’s memory difficulties. Len and Lucy have good family ties and support, which helps them to focus and maintain their relationship with one another.

#### *Case 5. Thelma and Tom*

Thelma’s memory problems have been progressive over a number of years. Tom stated that she no longer has the desire or energy to cook. Thelma also has a terrible sense of time. Although this is a challenge for Tom, he stated, “sometimes I blow up and apologize and we kiss and make up.” Tom is annoyed when Thelma says that she will do something and does not complete a task. But, he realizes that it is something she cannot control. Tom is constantly reminding Thelma to do things; he stated, “I fuss about it and then I kiss her and tell her I love her.” Tom indicated that most of the household responsibilities are his job. They have always had a service clean their house once a month. Together, they enjoy participating in activities including attending religious services, dancing, and traveling. Tom and Thelma also enjoy eating out. Tom

believes that Thelma is a good person and that they care for each other greatly. When it comes to thinking about the future, Tom is terrified to think about anything happening to Thelma.

Relationship synopsis: Tom's responses indicated commitment to his marital relationship with Thelma. He is frustrated and stressed with this situation; however, he tries not to let this get in the way of his relationship with Thelma. He stated, "You just have to be patient and you have to let it out some place, but you shouldn't let it out on your partner. You have got to get rid of frustrations somehow." Earlier in their marriage, Tom and Thelma had equal division of household responsibility. Currently, the majority of the tasks now fall to Tom. Although he expressed some negative emotional responses, he is quite content with their relationship. Tom's descriptions of their interactions suggest that they have a strong emotional bond and support for one another. Tom believes that their relationship as a whole is "stronger than ever." He attributes this to the care and support that they have for one another. Unlike the other cases in this study, Tom is the only spouse to describe aspects of physical intimacy (e.g., affectional gestures) and affection (i.e., verbal displays) within the marital relationship.

#### *Case 6. Harold and Helen*

Helen first noticed personality changes and expressions of anger in Harold about 3 to 4 years ago. She said that he simply cannot remember things like he did in the past. Harold used to participate in hobbies, such as building projects but has gradually stopped. According to Helen, Harold made the decision to go to the memory clinic. In the beginning, she did not go with him to any of his appointments. He did not want her

to go, which caused Helen some frustration. Recently, Harold consented to Helen going with him to the clinic. She views this as a move in a positive direction. She stated that, “he felt my concern and he got the feeling that I was there to support him in any way that I could.” Helen still works part-time as a real estate agent but has been working less time in order to be home with her husband. When Harold retired a few years ago, he took over doing the household finances; however, Helen believes he cannot handle this task. This causes conflict and tension between them. She does not say anything to Harold for fear that it may upset him. She is frustrated that he does not pay the bills or pays them twice. The neurologist at the memory clinic suggested that they write the checks together. Harold was extremely resistant to this idea. For Harold, realizing that he can no longer effectively handle the household finances on his own was another indication that he was losing ground. Together, they worked out a plan in which Harold will write the checks and then show them to Helen before mailing them. Helen believes that paying the bills will be the last thing that Harold will give up, or it will be something that she will have to take away from him, when the time comes. Helen admits to being more anxious around Harold, “kind of like you are with a child and that’s probably not a good thing.” Because Harold’s contributions to the household have decreased, he gets very frustrated and angry. Although his psychologist had assured Helen that these changes are normal, she indicated “because he has always been a gentle man, it’s hard.” Helen tries to initiate activities and push Harold to be more active. She believes that if she did not initiate activities, he would sit in a chair all day and do nothing. Helen said that there is a lot less communication between them now than in the past because Harold is so different from the way he has always been. The couple continues to travel

together, which is an activity that they have always very much enjoyed. They receive household help, including cleaning, every other week. Because Helen continues to work, she believes that this arrangement is easier than to hassle with Harold about who does what. Aside from handling the finances, Harold also accepts doing the dishes as his job as his assigned responsibility. Helen has been contemplating retirement, but in the mean time, lives life day-to-day.

Relationship Synopsis: Helen and Harold's relationship has experienced several changes because of Harold's memory problems and related personality changes. Helen believes that Harold is a different person, which has resulted in less communication and more conflict in their relationship. Helen serves as the initiator in the relationship; she encourages Harold to become more actively involved in daily life. Harold's frustration with not being able to do things he once did places a strain on their relationship, which results in Helen experiencing negative emotional responses to the situation (e.g., conflict and tension; frustration; stress). Harold insists on handling the household finances but is unable to complete this task effectively. Because Helen continues to work, they have hired household help every other week. In addition to the finances, Harold also helps with the dishes. The changes in their everyday life have negatively influenced their marital relationship and have increased negative emotions for Helen.

#### *Case 7. Jack and Jean*

In 1999, Jean noticed that her husband, Jack, was not remembering things as he used to. Jean said, "It is [his] short-term memory." She indicated that Jack is very social, which allows him to cover up for his memory loss. They travel together and often with other couples. Jean is unsure of how often they will travel because his memory

problems have gotten worse. She has always had to encourage Jack to participate in activities on their trips. He has always done most of the driving; now Jean is the principal driver. She also has taken over doing the yard work. Those responsibilities have shifted within their household; Jean has always been responsible for the household finances, grocery shopping, and cooking.

Jack has always participated in golfing and other sports with his friends. Recently, he gets aggravated because he believes that he is unable to successfully engage in these activities. As a result, his temper has a tendency to flare. Jean understands that the situation must be difficult for him because of the things he has had to give up. She stated, "I guess when you lose one function, it makes you upset with life." Jean believes that because Harold is becoming less socially active, more memory problems are likely to occur. Jean views herself as being a caregiver, "nurturing and taking care of somebody." However, she stated that she would enjoy it very much if she were able to travel and visit her daughter and granddaughter more often. She is limited on what she is able to do because of Jack's memory difficulties.

Relationship Synopsis: Jean encourages Jack to partake in certain activities and remain socially active. She takes the mindset that memory is a "use it or lose it" function. Although they still travel together as a couple, Jean worries that they will no longer be able to participate in this shared activity much longer. She expresses negative emotions such as frustration and stress, in response to dealing with Jack's memory difficulties. Jean enjoys doing lawn work, which is now her primary responsibility. She is slowly assuming more household duties than she used to. Jack is only responsible for

his own personal care. According to Jean, this shift in household tasks is working for them.

### *Case 8. Mike and Mary*

About four years ago, Mary noticed that Mike's short-term memory was deteriorating. She believes that the problems are a result of several strokes that he had over the past few years. Since then, he has been taking Aricept to ease the severity of his memory difficulties. According to Mary, taking Aricept has had a very positive impact on Mike's memory and a negative impact on his energy level. Mary has noticed that Mike is not alert, something that she is not used to seeing in her husband. She stated, "It is hard for me to take, not the emotional [sad] part; I am angry." Mary is not sad about Mike's memory problems; rather, she is angry and frustrated with the situation (i.e., having to repeat everything). She believes that Mike does not like her anymore. She feels more like his enemy, rather than his wife.

Mike has been experiencing multiple health conditions (e.g., heart attack, cataracts) in addition to the memory difficulties. He used to enjoy cross-stitching; however, his cataracts are interfering with his ability to see well enough to cross-stitch. Mike also used to play the organ, which he gave up because he believed that everyone in the class was ahead of him. Mary suggests that Mike is losing confidence. Mike's actions and behaviors often bother Mary. "It is hard to handle," she stated, "but we will [handle] it together and we will do the best we can."

Relationship synopsis: Although Mary's responses indicate a "we" relationship, she expressed feeling like an enemy rather than a wife. Her frustration with the situation leads to negative emotions. Mary indicated that if they have an argument, Mike

suddenly stops as if nothing had even happened. This bothers Mary; she wants to say something and get her point across. Mike previously did the grocery shopping, but has recently lost interest in this activity. According to Mary, Mike is handling the finances far better than he has since the memory problems started, which she attributes to his medication. They receive household help every two weeks. Mike often gets angry at Mary because she is not handling her responsibilities as she has done in the past. Previously, she would devote everyday to a different household task. She stated, "That used to be my life; that is not my life anymore." Mary is employed and has indicated that she does her household chores on her own time. Mike and Mary's communication style suggests a lack of an emotional bond. They do not spend much time together as a couple and when they do, negative emotional responses occur.

#### *Case 9. Orrin and Olivia*

Olivia realized about two years ago that Orrin's comprehension skills were not as good as they used to be. Orrin always had a lot of energy, but now he is frequently tired. Once she was told of Orrin's diagnosis of MCI, Olivia expressed great concern. Orrin was always in charge and took care of everything. Olivia has had to take on more and she has a tendency to worry about completing the household duties. Recently, Orrin had a falling accident that resulted in a hospital stay. Doctors suggested that he move into a rehabilitation center in an assisted living facility. Olivia and Orrin now live separately, although Olivia is in the process of searching for housing for the two of them. Living apart is very difficult for her. Orrin had always taken care of Olivia and she wishes that she could reciprocate that care. They have always shared household responsibilities except for the family finances, which Orrin handles because that is what

he used to do for a living. Together, Orrin and Olivia enjoy ballroom dancing and socializing with others. They also are content with their own individual activities. Olivia believes that Orrin's memory difficulties have affected their interactions with one another. She stated, "I have to keep everything simple, not to confuse him, because I noticed that he would get confused.

Relationship synopsis: Olivia and Orrin have always been able to discuss and communicate openly. Together, they made decisions and shared household responsibilities. During the interview, Olivia expressed the emotional closeness, support, and concern that she had for Orrin. She indicated a wish to reciprocate the care that Orrin has given her in previous years. Olivia is frustrated because of their current living situation. Olivia is no longer able to drive and believes that it would be better for them to live closer to the hospital and grocery stores. She has looked into assisted living facilities, but finds the cost prohibitive. In the meantime, she continues to live one day at a time.

#### *Case 10. Walter and Wendy*

Two years ago, Wendy began noticing changes in Walter's memory. His forgetfulness and lack of energy have been progressively getting worse. Wendy believes that tragic events in their family (i.e., death of their son, grandson's car accident, daughter's fight with cancer) have exacerbated these memory difficulties. Walter is aware of his memory loss and his visit to the memory clinic was self-initiated. Although he forgets times and events, Wendy said that he is very much involved in family genealogy, which she believes is a positive thing. Wendy holds a full-time job but is planning to retire because of Walter's situation. She believes that "it is better to leave

than to wait until it affects (her) job performance.” Wendy has always been the “secretary of the family.” She writes the checks and handles the household finances. Living on a farm, Walter had always dealt with the farming taxes; however, Wendy noticed this year that it was taking him a long time to do the taxes. She talked to Walter about it and both of them decided that it would be better for Wendy to take over the taxes as well. They make decisions together by discussing important matters. Wendy stated that Walter “has always depended on [her] a lot for [her] judgment and opinion.” Wendy does not want to make Walter feel incompetent but she has left fewer chores and things for him to do over the past three to six months. She stated that “at this particular point it has not hurt our adult [marital] relationship...it has not been like I am the caregiver and he is incompetent...we both have been very gentle with each other.”

Relationship synopsis: Wendy does not dwell on negative relationship outcomes. She did not indicate any conflict or tension in her relationship with Walter. Rather, she described how she has adapted to the situation. Walter’s memory and his constant questioning and requests to repeat things are sometimes frustrating, but Wendy tries to work on ways to not let them get to her. Walter and Wendy’s decision-making style reflects strong socio-emotional intimacy (i.e., companionship, commitment, closeness). The couple has not made any major household changes, as Wendy has always been the family secretary. Wendy has, however, taken on the task of doing the farm-related income taxes. Wendy believes that by simplifying the situation, both she and Walter are able to enjoy life to its fullest.

## Conclusion

While some spouses were more specific in talking about their marital relationship, others addressed their relationship more globally. However, all of the couples expressed change and stability within various aspects of their marital relationships. The dynamics of their interactions and communication style, expressions of intimacy, and division of household labor were influenced by either the level of the elder's memory difficulties or the individual health issues of the spouse.

Frustration was an emotion expressed quite often in the spouses' responses. Most often, the frustration described by the spouse stemmed from the aggravation that the elders experienced due to lack of their own ability to do something that they had previously done. For some spouses, MCI tended to accentuate the "annoying" personality characteristics of the elder.

Conversely, spouses' use of "we" language illustrated commitment within their marital relationship. The concept of couplehood suggests that spouses felt emotionally connected to the elder. In addition to commitment exhibited by spouses, they also mentioned participating in shared activities. Engaging in joint activities helped the couples maintain a level of companionship with one another. These positive relationship outcomes hint towards aspects of socio-emotional intimacy, which includes companionship, commitment, affection, and emotional closeness.

Role transitions were evident in the division of household responsibilities. Six of the ten spouses reported receiving external help. Some spouses stated that they have always received household help, while others have recently sought household help due to interferences with their own jobs. Seven of the ten spouses reported that they have

assumed greater household responsibility. For one spouse, all household responsibility has shifted entirely to the elder. Spouses' perceptions of their roles as asynchronous or synchronous have implications for how well they adapt to the influences that memory impairments have on the dynamics and interactions within their relationship.

Practitioners need to attend to the unique stresses and strains of living with a spouse with mild cognitive impairment and pay attention to effective coping strategies that are employed by these couples in order to minimize the negative influences that cognitive impairment has on marital relationships.

Spousal Perceptions of Mild Cognitive Impairment (MCI):

'Taking it One Day at a Time'

## **Abstract**

This article examines the influence of mild cognitive impairment (MCI) on interactions among long-term married couples. Ten spouses (5 wives, 5 husbands) of community-dwelling persons diagnosed with MCI reported on shared couple activities, amount of time spent together, division of household tasks, and management of everyday life.

Transcripts were analyzed through an open coding process. Analyses revealed both stability and change within marital relationships in terms of relational interactions, relational dynamics, socio-emotional intimacy, and division of household responsibilities. Findings suggest that having a spouse with memory loss yields negative emotional responses including helplessness, frustration, sadness, and worry. Longitudinal research is needed to further examine the changes in the dynamics of marital interactions when one spouse has mild memory loss.

## 1. Introduction

Mild cognitive impairment (MCI) refers to age-related decline in memory and other cognitive processes. It is a relatively new diagnosis used to identify cognitive changes that do not necessarily interfere with daily activities or the maintenance of social relationships with others (Petersen, Smith, Waring, Ivnik, Tangalos, & Kokmen, 1999).

When faced with a diagnosis of MCI, families are often shocked and horrified because they are uncertain of the diagnosis and the changes that might occur in their loved one (Kuhn, 1998). They are frustrated by the changes in memory experienced by their family member, as well as the ambiguity that the future holds. This is particularly true for spouses, as their daily lives are influenced by changes in their marital roles and relationship. When one member of the spousal dyad begins to experience cognitive decline, the non-impaired spouse may take on a managerial role, with the intention of helping to “manage” their partners’ emotional and behavioral changes. This newly created role can lead to feelings of burden, stress, or depression. Furthermore, the non-impaired spouse may also be experiencing health problems of his or her own, which can compound these negative emotional outcomes.

The purpose of this study was to examine the influence of MCI on marital relationships. Using social exchange theory as our theoretical lens, we examined interactions, intimacy, and division of household responsibilities in marital relationships and how MCI influences these exchanges. Examination of these interactions will inform researchers and clinicians about the issues and concerns that couples have at this early stage of cognitive impairment.

## **2. Social Exchange Theory**

Emerson and Cook (1978) posited that exchange of social interactions is the fundamental aspect of human development. Under this premise, people interact with others to benefit from the exchange. The nature of the relationship depends on the extent to which exchanges take place. There are intrinsic motivations (e.g., innate motives that drive persons to communicate, personally rewarding or enjoyable to individuals or the relationship) to interact with members of one's relationship network. If the member believes that the interaction will be personally beneficial, then it is more likely that an exchange will take place. Extrinsic motivations (e.g., tangible rewards) also can influence the likelihood that an interaction will take place but are ultimately due to intrinsic motivations (1978).

Thibaut and Kelley (1986) further expanded the theory to involve exchanges within the dyadic relationship that are interdependent and influence the psychological costs and rewards of the interactions. Costs include feelings of helplessness, conflict and tension, or anxiety. Conversely, rewards include feelings of contentment, pleasure, satisfaction, or happiness. These costs and rewards occur in the context of mutual exchanges that take place within the dyad. They are complex and variable, and may influence the relationships in different ways that distinguish themselves from the dynamics of other relationships.

We extended the utility of social exchange theory, which has primarily focused on younger, healthy couples, by examining older spousal relationships where one member of the spousal dyad has mild cognitive impairment. Findings from evidence and theory-based research suggest that aspects of marital relationships (e.g., commitment,

communication and interactions, emotional closeness) in later life are balanced by these mutual exchanges and that the challenge of coping with cognitive impairment is overcome by perceptions of reciprocity (i.e., beliefs about mutuality) within the relationship (Dwyer, Lee, & Jankowski, 1994; Townsend & Franks, 1997; Wright, 1993). More specifically, we explored how MCI influenced perceptions of intimacy and division of household labor and the non-memory impaired spouses' perceptions of exchanges within their marital relationships. These relationship aspects were chosen because social exchange theory lends itself to these dimensions of everyday social life. Perceptions of the costs and benefits of their relationship are influenced by the challenges of having a spouse with physical or mental impairments.

### **3. Previous Research**

Previous research addresses changes and adjustments in the marital relationship when one member of the spousal dyad faces dementia (Wright, 1993). Most of this research focuses on the burden and negative psychological outcomes (i.e., depression, stress) of providing care to persons with mid- and late-stage dementia. Although there are a few studies of families coping with the early stages of dementia, formally recognizing issues of care for persons with mild cognitive impairment represents a new area of study, which will advance understanding of the issues and concerns of spouses providing increased support and assistance to their partners.

Although early AD is distinct from MCI, the literature in this area serves as a starting point for understanding the influence of cognitive decline on marital relationships. The following review of literature focuses on the dynamics of spousal caregiving and includes a discussion of how assuming the caregiver role influences

perceived levels of intimacy and the division of household labor in the marital relationship.

### *3.1 Spousal caregiving*

The majority of the literature pertaining to spousal caregiving focuses on individual caregiver outcomes including burden, stress, and depression (Bedard et al., 1997; Majerovitz, 1995; Morris et al., 1988; Wright, 1994). For example, Majerovitz (1995) examined the role of family adaptability as a moderator for psychological adjustment. Findings from standardized interviews with 54 spousal caregivers of persons with varying levels of cognitive impairment suggested that for less adaptable caregivers, longer hours of perceived care were highly related to greater depression. Less adaptable caregivers were individuals who avoided the care recipient situation, were rigid in their family role, and were reluctant to change. In addition, greater caregiving stress was also associated with greater likelihood of depression. Similarly, Bedard and colleagues (1997) found caregiver burden positively correlated with frequency of patients' behavior problems. Conducting interviews at two different times, once at baseline and then at a follow-up interview scheduled 1 to 12 months after the initial interview, they found that male caregivers were more likely than female caregivers to report reduced levels of caregiver burden at the follow-up interviews. This could be explained by the fact that women are more likely to be in a caregiving role and men are not used to dealing with their new caregiving situation. However, it is difficult to compare those individuals interviewed one month after the initial interview with persons interviewed twelve months after the initial interview. The extent and range of the

changes in caregiver burden is highly variable and may not be reflected over a shorter period of time.

There is an abundance of literature pertaining to caregiver burden (e.g., Clyburn et al., 2000; Goodman, Zarit, & Steiner, 1997; Stuckey & Smyth, 1997; Zarit, Reever, & Bach-Peterson, 1980), the majority of which explored predictors and degree of burden. Researchers typically assess burden, depression, and stress using various standardized measures (e.g., Zarit Burden Interview, Memory and Behavior Problems Checklist, and Depression Rating Scale). Although this approach provides evidence of the burden of caregiving, it does not always capture the extent to which burden interrupts the caregivers' lives and relationships. The use of qualitative methodologies, either alone or in conjunction with quantitative approaches, is necessary to gain further insight and enhance understanding of the burden in spousal caregiving relationships.

Overall, the research on caregiving and marital relationships suggests differences in the ways in which husbands and wives respond to their caregiving roles and responsibilities (Kramer & Lambert, 1999; Lewis, 1998; Rudd et al., 1999; Rose-Rego, Strauss, & Smyth, 1998; Wright & Aquillino, 1998). Burden, stress, and depression are common outcomes for spousal caregivers, with wives who provide care typically reporting higher levels of psychological distress than husbands. The dynamics of marital relationships also change as one spouse assumes more responsibility for the care of the other.

### *3.2 Intimacy and caregiving*

Intimacy in caregiving represents a level of companionship, affection, commitment, and emotional closeness as perceived by spouses of persons with

cognitive impairment (Allen et al., 1999; Townsend & Franks, 1997; Wright, 1993).

Wright (1993) explored marriage through intimate accounts of couples dealing with AD. She identified three aspects of intimacy: (a) companionship, (b) affection or sexual intimacy, and (c) commitment. When one spouse experiences memory problems, interactions and exchanges within the marital relationship that contribute to each aspect of intimacy often change and may become asynchronous. The asynchronous nature of the relationship influences the level of reciprocity perceived by each of the members of the spousal dyad. For example, spouses with memory loss also may experience social isolation because they have difficulty effectively interacting with their partners. They may exaggerate frequency of sexual contact, possibly due to embarrassment, wishful thinking, and a longing need for closeness. Wright described couples who deal with cognitive impairment as living together, although in different worlds. The caregivers adapt by accepting their new roles and compensating for things otherwise lost.

Townsend and Franks (1997) suggested an additional aspect of intimacy, emotional closeness. Emotional closeness involves feelings of togetherness and wholeness as experienced by spouses who care for persons with cognitive impairment. Examining the experiences of spouses caring for persons with cognitive or functional impairments, the authors concluded that emotional closeness was the basis for establishing an intimate relationship. Greater levels of cognitive impairment lead to lower levels of perceived emotional closeness by spousal caregivers. This is particularly due to the high amounts of social isolation that spousal caregivers often face. Emotional closeness provides safety and understanding as every dyadic relationship goes through the life stages.

One critique of the intimacy and caregiving literature is that researchers use different terminology when referring to matters of intimacy. How they define intimacy depends on the caregiving situation and the context in which it is used and varies across relationships. In addition, researchers use various measures to assess the importance and meaning of intimacy in caregiving relationships (Townsend & Franks, 1997; Wright, 1993). As a result, it is difficult to generalize the findings across studies. Because intimacy has a high personal meaning and interpretation varies, qualitative methodologies provide an opportunity to capture the meaning and perceptions of intimacy within caregiving relationships.

### *3.3 Division of household responsibilities*

A review of the literature presented from 1989 to 1999 by Coltrane (2000) provides insight into the gender construction and theoretical ideologies underlying household labor. Household responsibilities involve dimensions of domestic labor (i.e. cooking, cleaning, grocery shopping, childrearing, handling finances). Coltrane (2000) ascertained that employed women are doing less housework than before and that husbands are doing somewhat more housework. However, women still do at least twice as much routine household labor as men.

Landmark studies (e.g., Bernard, 1972; Blood & Wolfe, 1960; Oakley, 1974; Vanek, 1974), as well as review articles (e.g., Coltrane, 2000; Kamo, 2000; Osmond & Thorne, 1993; Shelton & John, 1996; Thompson & Walker, 1989) on division of household labor focus on younger and middle-aged couples. Findings from these studies and reviews suggest that while husbands continue to do less housework than wives, their contributions are increasing at a slow pace. Variables such as family size,

age of the couples, life stage, ethnicity, and the presence and contribution of children affect the allocation of labor within a household.

Only two empirical studies were found in the family gerontology literature that examined division of household labor between older couples. In 1995, Pina and Bengtson interviewed retired women who spoke of their household responsibilities in terms of support by husbands, marital happiness, and gender ideologies. Perceptions of spousal support mediated the relationship between division of labor and wives' psychological well-being. Wives reported less spousal support when division of labor was perceived as unequal, which, in turn, led to lower levels of marital satisfaction and happiness. The authors concluded that ways in which division of labor influences wives differs for those previously employed compared to long-term homemakers.

Wright (1993) examined division of household labor in marital relationships in which one member had cognitive impairments. As spouses' memory declines caregivers typically take on more of the household responsibilities. Most of the conflicts that arose from household tasks were due to caregiver expectations about their roles as well as their spouses' roles in the home and to changes in lifestyle and money management. Because of the toll that Alzheimer's disease (AD) had on their partner, spousal caregivers took on a more worried and protective manner when dealing with matters of money. According to Wright (1993), timing of events is a major determinant of development and how people perceive their social relationships with others. Couples who experience asynchronous timing of life events are more likely to experience conflict associated with the burden of household labor than those couples who experience synchronous timing of events in later life. Because of assuming extra responsibilities

through the asynchronous timing of events, caregivers often perceive their relationships as conflicted. By considering household responsibilities in relationships where one spouse has cognitive impairments, we are able to gain a deeper understanding of the social, emotional, and psychological influences on the spousal caregiver.

### *3.4 Summary*

Spousal caregiving research provides insight into the influence of moderate to severe memory loss on individual well-being and marital relationships. Study samples consist of participants with varying levels of cognitive impairment and do not compare outcomes by impairment levels; thus limiting the generalizability of the findings (Barber, 1993; Lewis, 1998; Majerovitz, 1995; Morris, Morris, & Britton, 1988; Townsend & Franks, 1997). Research involving husbands and wives as caregivers suggests differences in the ways in which they approach caregiving, as well as the ways in which the caregiving role influences their lives (Kramer & Lambert, 1999; Rose-Rego et al., 1998; Wright & Aquilino, 1998). The spousal caregiving literature represents a broad depiction of the experiences of spouses who provide care for their partners. Some aspects of relationships require more in-depth attention through face-to-face interviews to appreciate the diversity of spousal relationships. We explored the influences that mild cognitive impairments have on marital relationships by focusing on aspects of intimacy, interaction, and division of household labor in marital relationships. Specific research questions addressed how spouses of persons with MCI: (a) perceive stability and change within their marital interactions, (b) describe intimacy within their relationship, and (c) experience division of responsibilities and tasks within the household.

## 4. Methods

Prior to the start of data collection, the Virginia Tech Institutional Review Board (IRB) reviewed and approved this research. It involved a secondary analysis of data from a larger project entitled, *“Caregivers of Persons with Mild Cognitive Impairment: Information and Support Needs.”*<sup>1</sup> This short-term longitudinal study (2004-2006) consists of three phases: (1) initial interviews with the person with MCI, the spouse, and the secondary family member, (2) six-month follow-up interview with the primary family member, and (3) one-year follow-up interviews with both the primary and secondary family members.

In collaboration with memory clinics located in southwest Virginia, the goal of the larger project is to identify 100 individuals with MCI. The clinics use a battery of measures to determine the presence of MCI including: (a) MMSE (score of 24 or higher), (b) difficulty with activities of daily living (ADLs) (i.e., toileting, bathing, dressing), and (c) difficulty with instrumental activities of daily living (IADLs) (i.e., managing a checkbook, cleaning, cooking). Once a person with MCI (referred to as the elder) agrees to participate in the study, we conduct a brief interview with him/her and a longer, more in-depth interview with his/her primary family member (i.e., spouse/partner, adult child). In addition, the primary family member completes a series of self-report measures.

### 4.1 Study sample

From 43 of the families enrolled in the study as of February 2005, 20 involved spouses or partners as the primary family member (13 wives and 7 husbands). Prior

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<sup>1</sup> This research was supported by a grant (Project #IIRG-03-5926) from the Alzheimer’s Association. Principal Investigators: Karen A. Roberto & Rosemary Blieszner.

research suggests differences in the caregiving experiences of husbands and wives. To ensure equal representation of husbands and wives in the study sample, we used a random numbers table to select 5 husband and 5 wives.

Elders ranged in age from 66 to 86 years ( $M= 78.6$ ;  $SD= 6.64$ ). Spouses ranged in age from 65 to 89 years ( $M= 76.6$ ;  $SD= 8.30$ ). The number of years the couples were married range from 34 to 62 ( $M= 53.0$ ;  $SD= 8.31$ ). The education level of the spouses ranged from high school graduate or GED completion to graduate degree. All of the couples were white. Two spouses did not complete any of the standardized forms for the interview. See Table 2a for individual participant demographic information.

Table 2a

*Participant Demographics*

<i>Couple</i>		<i>Years Married</i>	<i>Age</i>		<i>Primary's Education Level</i>	<i>Household Income Level (per year)</i>
<i>Elder</i>	<i>Primary</i>		<i>Elder</i>	<i>Primary</i>		
Clara	Cliff	62	86	83	Graduate degree	\$48,000-\$83,999
Dena	David <sup>a</sup>	58	77	-----	-----	-----
Joy	John <sup>a</sup>	53	-----	-----	-----	-----
Lucy	Len	61	86	89	Graduate degree	-----
Thelma	Tom	34	85	83	Bachelor's degree	\$48,000-\$83,999
Harold	Helen	48	76	69	1-3 years of college	\$120,000 +
Jack	Jean	54	74	72	Trade school	\$12,000-\$23,999
Mike	Mary	55	76	72	1-3 years of college	\$48,000-\$83,999
Orrin	Olivia	58	81	80	High school or GED	\$24,000-\$47,999
Walter	Wendy	47	66	65	High school or GED	\$48,000-\$83,999

<sup>a</sup> Did not complete the background demographic sheet.

*4.2 Measures*

The data used for this study came from interviews with the primary family member; thus, they represent the non-memory impaired spouse's perspective of the influence of memory loss on the marital relationship. Sociodemographic information included age, education, annual income; number of years married and number of marriages was used to describe the sample. With the exception of Tom and Thelma, who are in their second marriage, this is the first marriage for all of the couples. Open-ended interview questions that focus on issues specific to the marital relationship

included: (a) range of activities participated in as a couple, (b) amount of time spent together, (c) division of household responsibilities, (d) ways of showing care or affection towards one another, and (e) management of everyday life. We framed the questions to assess stability and change in the marital relationship since the onset of memory problems. All interviews were tape-recorded, transcribed verbatim, and verified by re-checking the tape-transcription correspondence.

In addition to participating in the semi-structured interviews, the spouses completed three standardized scales (see Table 3a). Their responses to these measures provided information about the memory and behavioral changes of the elder as it relates to the outcomes for and responses of the spouse. The *Revised Memory & Behavior Problems Checklist* (RMBPC: Teri et al., 1992) is a 24-item scale in which the spouse rates the occurrence and severity (1 = a little; 2 = moderately; 3 = very much; 4 = extremely) of a series of problematic behaviors that the person with MCI is likely to exhibit. Severity indicates how bothered the spouses are by the exhibited behavior. Overall, the measure has satisfactory validity; reported alpha coefficients range from .67 to .90 (Teri et al., 1992). For the present study, the alpha coefficient was .80. Common memory and behavior problems exhibited by the elder included: (a) asking the same question over and over, (b) having trouble remembering recent and past events, (c) losing or misplacing things, (d) forgetting what day it is, (e) experiencing difficulty concentrating on tasks, and (f) appearing anxious or worried. The total number of memory and behavior problems was calculated by summing the items. The frequencies of the memory and behavior problems are shown in Table 4a. We determined severity

of the memory and behavior problems by multiplying the total memory and behavior problems by the participants' average bothersome score.

The short form of the *Zarit Burden Interview* (Bedard et al., 2001) was used to assess the extent to which the spouses or partners felt burdened by their role and relationship with the person with memory difficulties. Scores range from zero to 48, with higher scores indicating higher levels of burden. The reported reliability coefficient for this 12-item scale is .88, which is comparable to that of the full version of the scale (.83 to .91) (Zarit et al., 1987). For this study, the alpha coefficient was .91.

The *Center for Epidemiological Studies-Depression Scale* (CESD: Radloff & Teri, 1986) provides evidence of depressive symptoms of the spouse. We used the yes-no format of this scale, which had comparable reliability and validity as the original four-point Likert rating scale (Blazer, Burchett, Service, & George, 1991). Scores range from zero to 20 with higher scores signifying greater levels of depression; a cut-off of 9 indicated depression. When used to assess depression in community-dwelling older adults, reliability coefficients range from .85 to .91. For the current study, the alpha coefficient was .76.

Table 3a

*Participant Scores on Standardized Measures*

<i>Couple</i>					
<i>Elder</i>	<i>Primary</i>	<i>Memory/Behavior Problems (N)</i>	<i>Problems Bothersome (M)</i>	<i>Burden</i>	<i>Depression</i>
Clara	Cliff	5	0.00	3	4
Dena	David <sup>a</sup>	-----	-----	-----	-----
Joy	John <sup>a</sup>	-----	-----	-----	-----
Lucy	Len	6	0.96	5	4
Thelma	Tom	3	6.00	0	7
Harold	Helen	13	10.01	16	5
Jack	Jean	15	30.00	25	5
Mike	Mary	5	2.00	8	4
Orrin	Olivia	9	12.24	10	8
Walter	Wendy	5	5.00	2	4

<sup>a</sup> Did not complete the standardized scales.

Table 4a

*Frequencies of Memory/Behavior Problems*

<i>Memory/Behavior Problem</i>	<i>Frequency</i>	
	<i>Husbands</i>	<i>Wives</i>
Asks the same question over and over	2	5
Trouble remembering recent events	3	5
Trouble remembering past events	2	4
Loses or misplaces things	3	3
Forgets what day it is	2	3
Starts, but does not finish things	1	2
Difficulty concentrating on a task	1	3
Destroys property	0	1
Wakes you or other family members at night	0	1
Talks loudly and rapidly	0	3
Appears anxious or worried	0	3
Engages in potentially dangerous behavior	2	1
Verbally aggressive to others	0	2
Appears sad or depressed	0	3
Expresses feelings of hopelessness	0	3
Crying and tearfulness	0	2
Comments about death of self or others	1	0
Talks about feeling lonely	1	0
Comments about feeling worthless	0	1
Comments about feeling like a failure	0	1
Arguing, irritability, and/or complaining	0	3

*4.3 Data coding and analysis*

Following multiple readings of the transcripts, we utilized an open coding process to generate a list of themes and patterns. The coding scheme underwent four iterations before the team had consensus. We reached 100% agreement for five major coding categories: dynamics of the relationship, relationship outcomes, socio-emotional intimacy, physical intimacy, and division of household responsibilities. The final coding scheme was applied to each case. Social exchange theory provided the conceptual framework for linking participants' responses to the research literature and for keeping

the focus of the coding and analysis on data specific to the purpose of this study (Yin, 1989).

#### *4.4 Trustworthiness*

To achieve credibility, we employed strategic investigator triangulation, through which others provided feedback on the coding scheme and its application to the transcripts. The interviewer completed member checks with each interviewee throughout the process as a form of credibility. Because participants were selected for participation in this study if they were married and were dealing with memory loss, the information is transferable to similar couples. Thick description of the individual couples' experiences was provided through the development of case summaries followed by a further cross-case analysis of the transcript data. Dependability was accomplished by employing the code-recode strategy. Each transcript was coded every time that the coding scheme was revised for a total of five coding revisions. Triangulation and peer examination of the coding scheme and transcripts also demonstrated the dependability of the current research study. A panel of experts (e.g., research team) confirmed the interpretations of the quotes as they contributed evidence to the findings of this study. Triangulation was used to demonstrate confirmability in this study. Data source and investigator triangulation supported the confirmability aspect of trustworthiness. Furthermore, the first author kept a journal consisting of the teams' thoughts and ideas that emerged during the process of the coding and analyzing the data for the project. We were aware of our own research biases, interests, and preconceptions throughout the extent of this qualitative case study analysis.

## 5. Results

The spouses in this study expressed both change and stability within aspects of their marital relationships. The level of the elders' memory difficulties influenced the dynamics of the couples' interactions and communication style, expressions of intimacy, and division of household labor. The three research questions that were addressed in this study are discussed individually and contribute to the study results: (a) dynamics of interactions within marital relationships, (b) socio-emotional and physical intimacy, and (c) division of household responsibility.

### *5.1. Dynamics of interactions within marital relationships*

#### *5.1.1. Decision-making style*

Mild memory problems may influence the elders' ability to make good decisions. The role the spouse plays in the relationship also influences how involved the elder is likely to be in the decision-making process. A variety of factors, including the level of memory difficulties the elder is experiencing and other health-related issues either the elder or the spouse is coping with, influences couples' decision-making styles.

Three of the spouses explicitly described their decision-making process. Although their strategies were distinctly different, changes in the ways in which decisions are currently being made were found for only one couple, Len and Lucy. Len said that he continues their life-long pattern of discussing decisions with Lucy, but he ultimately makes the final decision. Orrin and Olivia also have always shared in the decision-making process and continue to make decisions together. Conversely, Wendy has always been the decision-maker in their family. She said, "He [Walter] has always depended on me a lot for my judgment and opinion. He has abided by that for the most

part or whatever I think about things.” Walter served as an “outsider” to all of their major life decisions. Wendy has always sought advice from her parents for direction when making major decisions. Because Walter does not feel threatened by Wendy’s parents, seeking advice is a good strategy for them.

For the remaining seven couples there was evidence that the non-memory impaired spouse was taking on more responsibilities, including making most if not all decisions in the couples’ daily lives. For example, Helen works part-time and has decided on her own that it would be best to hire a maid to clean the house every other week. How couples divide household responsibilities often hints toward who holds the decision-making power.

#### *5.1.2. Negative relationship outcomes*

Both negative and positive emotional relationship responses to changes in the memory-impaired spouse and marital relationship were evident across all couples. Currently, their relationships are characterized by more negative expressions than positive ones. Seven of the ten spouses indicated conflict and tension, worry, stress, or frustration when dealing with their partner’s memory loss. Helen suggested that she finds that her attitudes toward Harold have changed since his memory problems began. She stated:

I am more anxious, [Harold] makes a lot of small mistakes and I find myself being a bit uptight about what mistake he is gonna make next...kind of like you are with a child and that's probably not a good thing, but again I don't know what do about that.

Because of Harold's "mistakes," Helen finds herself becoming angry and she is unsure of how to relax and let go of the negative emotions. She said that when she does correct Harold, he gets angry with her. She realizes that his anger is not with her, but rather it is resulting from his own frustration with his memory difficulties. This results in negative feelings for both members of the spousal dyad. The elders become stressed about their gradual lack of ability, while the spouses become irritated with the idea that this person is different from the person whom they married. For example, Mary stated, "I do get angry...I feel like he [Mike] doesn't like me. I feel like more of an enemy rather than his wife." Mary's anger stems from the changes in Mike's behaviors, actions, and personality. She sees him as a "different" person from the person she has shared her life. This frustration has led her to believe that something is wrong with her relationship with Mike.

For the spouses in this study, MCI often accentuated certain personality characteristics in the elders. For example, Len indicated his frustration with Lucy's stubbornness. He stated, "As far as stubbornness, she's still stubborn...yeah, she's not any different in that. [She] still has the same characteristics that she's had even before I married her." Although he perceives little difference in her personality and behaviors, Len's comments suggest that Lucy's memory problems coupled with her stubbornness are too much for him to handle. Her one personality trait that ordinarily did not bother him is now exacerbated by the memory problems and is more difficult for him to ignore. Similarly, David suggested that Dena's gradual loss of social support resulted from her increased tardiness. According to David, Dena has always made people wait for her when getting ready for an event. Although her tardiness has always been an issue, her

memory problems and other behavioral issues may exaggerate this personality trait. David expressed many negative emotions throughout the interview. His life-long relationship with Dena has been difficult and trying for him. When asked how long they have been married, David replied “58 miserable years.”

Unlike Len’s and David’s reactions to their wives, Tom is more understanding of Thelma’s behaviors because he realized that she may not remember. He stated, “I tried to ask her to do things that she says she is going to do, but she doesn’t...it annoys me and when it happens I have to realize that it’s something she can’t control.” His strategy is patience. Tom said, “You just have to be patient and you have to let it out some place, but you shouldn’t let it out on your partner. You have got to get rid of your frustrations somehow.” This patience could also be interpreted as a positive relationship outcome. While Tom is annoyed, he does not take these changes personally. He tries to understand his wife’s actions and behaviors and recognizes that they may be uncontrollable.

Three of the spouses expressed feelings of worry throughout their interviews. Len and Cliff indicated that they were worried about their wives’ future. They worried about the progression of the memory difficulties, as well as potential changes in their housing arrangement. Cliff stated, “It would be awful hard on me for her to go anywhere else because she doesn’t want to and I don’t want her to...I don’t want her to leave me.” On the other hand, John and Joy’s situation is unique in that Joy, the elder, is assuming greater household responsibility. John is worried that his health is placing too much strain on Joy. He believes that his blindness and hip problems are too much for Joy to

handle. For this couple, the spouses' health is the major cause for their role shifts and for his worry.

Kramer and Lambert (1999) examined husbands who transitioned into the role of caregiver for their wives with AD and found that the husbands tended to report low levels of marital quality and high levels of burden. All five of the husbands in this study indicated some type of negative relationship outcome. This suggests that even in these mild stages of memory loss, the husbands have assumed more responsibilities that were not part of their normal routines. The wives' need for increased support from husbands may represent a major transition in the marital relationship. For example, Tom stated that he has had to take on more household responsibilities. He must learn to adapt to new roles (e.g., cooking) that he did not traditionally perform.

While the intensity of wives' responsibilities increased, they did not experience as dramatic of a transition as did the husbands. Only two of the wives reported frustration, conflict, or tension within the relationship; however, their responses on the standardized measures indicated otherwise (see Table 2). Comparing the spouse's scores on the standardized scales, it became apparent that the wives reported more memory problems and behaviors than the husbands did. The number of observed memory and problem behaviors is not always directly related to the perceived severity of those problems, however. For example, even though Tom noted three problems, he is moderately bothered by these behaviors. Comparatively, Jean had observed 15 problems and is also moderately bothered by these problems. This may be explained by the traditional roles wives typically hold within the family; women are generally the caretakers within the family and are expected to manage family matters. The husbands

were bothered by having to take on tasks that appeared to take less effort (e.g., cooking, cleaning), but were ones they were not used to doing. Burden and depression scores were also much higher for wives than husbands. This finding is consistent with Rose-Rego and colleagues' (1998) findings that wives reported lower levels of psychological well-being and more negative outcomes related to caregiving (e.g., depression, stress, burden) than do husbands.

### *5.1.3. Positive relationship outcomes*

Although husbands were more likely to report more negative outcomes than wives were, no apparent gender differences were observed when examining positive relationship outcomes. Two spouses overtly referred to their relationship in a positive way. Wendy stated that Walter has always been gentle with her and that they have always cared for each other. Although Cliff expressed some frustration with Clara, he also stated that "if it [our relationship] has changed, it's better." It is unclear to what Cliff attributed the apparent improvement in their relationship.

Couplehood is a term that signifies a relationship in which the focus is on the couple, rather than the individual in the dyad (e.g., Kaplan, 2001; Kaplan, Ade-Ridder, Hennon, Brubaker, & Brubaker, 1995; Roberto, Gold, & Yorgason, 2004). This phenomenon is expressed using "we" language when referring to experiences of one member of the dyad, regardless of the context of the questions being asked. Four of the spouses talked about their situation, never separating themselves from their partner or describing them as individuals. For example, Len stated, "We had a test trial package [of anti-depressants] which we're running out of, which I have to call the doctor and ask for a prescription so we can continue that." His use of "we" suggests that they are both

making decisions about her taking the anti-depressant medication. The use of “we” indicates a strong commitment to the marriage and to their partner. These spouses are attentive to their partner's needs, thus creating more of an emotional bond to their spouse.

The comments of six spouses revealed that engaging in shared activities was likely to result in a strong emotional bond with their partners. Activities in which these spouses were likely to participate included traveling, socializing, dancing, and religious activities. For spouses, these shared activities created a sense of companionship. They expressed great enjoyment in their leisure time with their spouse. Two of the spouses reported a decline in the shared activities due to either the memory problems or their own health problems.

## *5.2. Socio-emotional and physical intimacy*

Embedded in all of the spouses' responses were aspects of intimacy. Socio-emotional intimacy included commitment, affection, companionship, and emotional closeness. The level and context through which each couple spoke of intimacy were different. Len mentioned that because he and Lucy lived in a retirement home, they spend a lot of time together. They also have individual activities that they engage in with friends; however, Len's description of their current relationship focused primarily on the amount of time they had spent together (i.e., companionship).

Support is another form of socio-emotional intimacy that the spouses mentioned. It can have both positive and negative outcomes. For example, Helen suggested that until recently, Harold did not want her to go with him to his doctor visits. She stated that, “the main thing that came out of that [her going with him] was that he felt my concern

and he got the feeling that I was there to support him in any way that I could.” Support, in David’s case, was expressed through his concern for Dena’s safety. David does not want Dena to drive anymore because she forgets how to get from point A to point B. Although she was angry with him about this decision, he stated, “I don’t think she should do it [drive]. Sooner or later she is going to have an accident and hurt someone or herself.” Much of the social gerontology research focused on negative relationship outcomes (e.g., burden, depression, stress) and concluded that the negativity weighs more heavily on social relationships than positive exchanges (Reinhardt, 2001).

Dyer and colleagues (2004) reported that in late life, spouses wished to “pay back” the other if they had received care or support earlier in life. This finding is also characteristic of the tenets of social exchange theory. Olivia expressed this type of reciprocal thinking. Olivia and Orrin are currently living apart because Orrin is undergoing in-patient rehabilitation following a heart attack. She stated, “He took care of me all the time and he’s the one who drove me to appointments or anything.” Wanting to reciprocate the care that Orrin has given her, Olivia said, “I wish I could take care of him.” Not being able to care for Orrin has been difficult for Olivia. Because Orrin is no longer at home, she has had to rely on help from her neighbors, which she dislikes because she hates to burden others. However, she is thankful for the social network that she has established.

A second aspect of intimacy that was mentioned by only one of the spouses was physical intimacy, which included physical displays of affection (e.g., hug, kiss) and expressions of sexual intimacy. Tom expressed that even though he becomes frustrated

with the situation of caring for his wife, Thelma, he continues to be close to her. He stated:

I try to remind her (to do something), to keep reminding her, of course, she's very indecisive about getting dressed and things like that...perpetually tardy. I fuss about it and then I kiss her and tell her I love her.

Tom also stated that he and Thelma care for each other greatly. Even though times may become stressful, he believes that their marriage is stronger than ever. Tom stated, "We just care for each other, she's just such a good person." Tom's love and expressions of care suggests a sense of commitment within his marital relationship with Thelma. Like Tom, all spouses had indirectly implied a sense of long-term commitment with their partners.

### *5.3. Division of household responsibility*

Spouses (i.e., spouses) spoke of the division of household labor in several different ways. Six of the ten spouses mentioned the use of external help (e.g., maid, housekeeper) as a way to manage household tasks. They relied on external help for different reasons. Memory difficulties ultimately triggered the decisions that these spouses made regarding the use of services. Helen has hired a maid every other week because of their current situation. Helen works part-time and Harold had lost interest in doing household duties. She stated, "It got to the point that he [Harold] did not want to do that [household work] and with my working, it was just easier to get somebody than it was to have a hassle about it." Similarly, David has also hired a maid for Dena. Prior to seeking help, David took on many household responsibilities that ultimately began to interfere with his ability to do his job effectively. He would get phone calls from Dena at

work and he would have to leave work to help her do something. The maid is now the one responsible for waking Dena, getting her dressed, and making her breakfast.

The three other couples mentioned receiving external help ranging in frequency from once a month to every week. For example, Cliff stated that Clara has a woman come in to help her clean for a half day on Friday mornings. The couple has known the woman for years and Cliff is comfortable with her helping Clara. Although Cliff and Clara receive external help one day a week, Cliff perceived that he and Clara have an equal division in their household responsibilities. He stated, “we both share in it some, not because she couldn’t, but I don’t have anything else to do much, so I sort of help too.” The three couples that receive minimal external help were quick to say that they are not messy; rather it helps them to keep on top of things.

Wright (1993) examined division of household labor in marital relationships in which one spouse had cognitive impairments. She found that at some point in the progression of the memory difficulties, responsibilities shifted to the non-impaired spouse. Seven of the ten spouses have begun to assume greater responsibility since the memory difficulties started. Tom and Thelma have a cleaning service to clean their home once a month. Despite this, he has taken on much more responsibility than before (e.g., cooking, cleaning, grocery shopping). In Orrin and Olivia’s case, Olivia indicated that Orrin was always in charge and took care of everything but he can no longer handle household responsibilities. She stated, “He still likes to be in charge, but it’s difficult for him...I have to take on more.” Orrin always handled the domestic finances, a task that was also part of his work life. Recently, Olivia has taken on the financial responsibility. She had to file their income taxes because Orrin is undergoing in-patient rehabilitation

following a recent heart attack. This has been particularly difficult for Olivia, as she has never had this “important” responsibility. Family caregivers often become worried and protective when dealing with financial matters, especially if they have not been in charge of this prior to their partner's memory problems (Wright, 1993).

Jean expressed both changes and stability in hers and Jack's daily life routines.

Jean said:

Well, of course he did most of the driving when we were together. I'm now the principal driver. I've taken over the yard work (laugh). I always did the budget and most of household, and shopping and cooking. You know, he dresses himself and feeds himself.

Jean was the only spouse who overtly characterized herself as a caregiver. She stated, “I kinda like doing things to my house and yard and taking care of somebody.” While Jean appreciates being a caregiver, Wendy does not think of herself as being in the caregiving role. She stated:

I don't want to make him feel incompetent on things...I guess in the last three to six months maybe I leave fewer chores for him to do in the way of making phone calls to get things done. And if I do, I leave a detailed message...But you know, at this particular point it has not hurt our adult relationship...It's not been like I am the caregiver and he incompetent and all of that.

Jean's use of the phrase “adult relationship” could hint toward the sexuality aspect of her relationship with Jack; although, it is not clear as to what she was referring to.

Across all of the couples, the wives encouraged their husbands to complete certain assigned household responsibilities. These wives believed that in order to maintain an active memory, their partners need to “use it, or lose it.” This mentality was evident throughout their interviews and held true for household responsibilities as well as social activities. For example, some elders displayed inactivity either because of a lack of desire or the belief that he/she no longer had the ability to engage in activities. Helen, like other wives in this study, was concerned about Harold’s inactivity. She said:

I have a feeling that sometimes if I just left him totally alone, he would do nothing except sit here and watch television or play solitaire on the computer...but it had just gotten to the point that he really was sitting in the chair in the den most of the time and that concerned me quite a lot.

In these situations, spouses initiated activities and tried to engage the elder to participate in activities and hobbies. They worried that inactivity would lead to more memory problems.

Wendy was the only spouse to indicate no changes in their daily household life. She noted that she has always been the secretary of the family. John and Joy represent a unique case with respect to household responsibility. John, the spouse, has recently experienced late-onset blindness; thus, he is no longer able to drive or do most of the household chores. Joy, the elder with MCI, has taken on more of the household responsibilities, despite her memory problems. John said, “she’s more or less confined, for what she needs to do for me...I know she’s tired out with me...she’s settled with household duties and it’s just too, too much...it’s a chore for her.”

The couples in this study adapted their previous lifestyle to meet the needs of their current situation. Although there were some similarities across the couples (e.g., hiring external help), each dyad developed unique strategies for managing the changes in their everyday lives. Traditional gender roles influenced their perceptions of an adaptation to division of household responsibilities. For most couples, the roles each spouse had earlier in life continued to be important as they learned to cope with changes in health and cognitive abilities.

## **6. Conclusions**

The couples in this study all expressed change and stability within aspects of their marital relationships. The dynamics of their interactions and communication style, expressions of intimacy, and division of household labor were influenced by the level of the elders' memory difficulties. The current definition of MCI suggests that there is minimal to no influences in the elders' daily and social lives (Petersen et al., 1999); yet, the elders in this study were having difficulty in managing some everyday activities as evidenced by changes in the decision-making process, household labor, and interactions with their spouses. There may be a progression of decline within MCI that might involve gradual changes in social relationships as well.

Spouses expressed more negative than positive emotional responses. Perhaps this is because people first notice the negativity in a situation before recognizing the positive (Boerner, Reinhardt, Raykov, & Horowitz, 2004). Although all of the husbands expressed feelings of frustration and helplessness with having a spouse with MCI, their scores on the standardized measures (e.g., burden, depression) were fairly low. The interpretation of these standardized scales is limited because only three of the five

husbands completed the scales. Conversely, only two of the five wives expressed negative relationship outcomes in the interview, but their scores on the standardized measures were much higher, which is consistent with previous literature suggesting that wives in caregiving relationships indicate higher levels of burden and depression than husbands do (Rose-Rego et al., 1998). However, previous literature has focused on caregivers' responses to having a spouse with AD. The findings of this study suggest that wives report high levels of burden and depression on standardized assessments even when their spouses' memory loss is mild, which may have implications for how they may deal with this in the future. Longitudinal research is necessary to examine changes in the levels of caregiver burden and depression if the elders' memory problems progress as adaptations to their new roles may become easier or more difficult.

Frustration was an emotion that came up quite often in the spouses' responses to questions about changes in their partners and their marital relationship. Their definitions of frustration and its level of intensity differed. Most often, the frustration expressed by the spouse was in response to aggravation with the elder as a result of their inability to do something that they had previously done. For some spouses, MCI tended to accentuate the lifelong "annoying" personality characteristics of the elder. The memory difficulties appeared to have increased the likelihood that the elder exhibited these traits, which in turn, caused the spouse to become easily bothered.

Indications of positive relationships were those in which spouses focused on aspects of socio-emotional intimacy. The spouses' use of "we" language illustrated commitment within their relationship to the elder. The concept of couplehood

demonstrated the idea that spouses felt emotionally connected to the elder (e.g., Kaplan, 2001; Kaplan, Ade-Ridder, Hennon, Brubaker, & Brubaker, 1995; Roberto, Gold, & Yorgason, 2004). However, the idea of couplehood could also hint toward a strong identity with one's marital relationship. In addition to commitment exhibited by spouses, they also mentioned participating in shared activities. Engaging in joint activities helped the couples to maintain a level of companionship with one another. These positive relationship outcomes hint towards aspects of socio-emotional intimacy, which includes companionship, commitment, affection, and emotional closeness.

Spouses expressed a wide range of mixed emotions. Through direct expressions of support and concern, their responses were either positive or negative. How and if their partners' memory loss influenced these emotions depended on the aspect of marital relationships (e.g., intimacy, interactions, perceived commitment). For example, support was mentioned in terms of providing care and companionship rather than providing instrumental support (e.g., bathing, dressing). Spouses were more positive when speaking of matters of providing companionship, but were more negative when referring to physical support and having to support their spouse more than they thought they would be needed. Thus, negative expressions of support may have more influence on the adaptation to caring for a spouse with memory loss than issues of positive aspects of support (Reinhardt, 2001).

Another aspect of socio-emotional intimacy was reciprocity. As suggested by social exchange theory, family members' perceptions of reciprocity positively influenced their ability to develop effective coping strategies for caring for a spouse with cognitive impairments. Although reciprocity is a mutual process, these exchanges are not

required to occur at the same point in time and do not necessarily involve giving and receiving the same things. For example, one member of the spousal dyad may need help or care early in the marriage. Later in life, the care receiver may end up providing care for the other spouse as a way to “pay them back” (Dwyer, Lee, & Jankowski, 1994).

The spouses were not directly asked about perceived physical intimacy because of the personal nature of the topic. Only one spouse mentioned his use of affectional gestures (e.g., hug, kiss) and verbal expressions of affection (e.g., saying “I love you”) with his wife. His use of physical intimacy suggests that his strategy for caring for his wife who has memory loss is to constantly remind her of his love for her. Furthermore, showing his love and affection may help to keep his patience and understanding. Future research should examine how mild memory loss influences changes in physical and sexual intimacy within later life marital relationships.

There is great variability in the ways in which couples divide household responsibilities. For one spouse, all household responsibility has shifted entirely to the elder. This occurred because the spouses’ individual health issues, including late-onset blindness and hip problems. This unique situation causes stress and frustration for both members of the spousal dyad. Six of the ten spouses reported receiving external help. Some spouses stated that they have always received household help, while others have recently sought household help due to interferences with their own jobs. Previous literature often suggests that caregivers seek external help as a last resort (Noelker, Ford, Gaines, Haug, Jones, Stange, & Mefrouche, 1998; Roberto, Allen, & Blieszner, 2001; Schoenberg, Coward, & Albrecht, 2001). Utilizing external help early on may be a

positive step in caring for a spouse with memory loss. This variability alludes to the idea that each of these couples dealt with their situation individually and adapted their roles to meet their needs within their marital relationship. This further illustrates the complexity of the caregiving situation.

The influences of traditional gendered roles were evident as the spouses discussed changes in roles within their marital relationship. For example, one of the wives referred to herself as a “caregiver” and enjoyed and took pride in knowing that she was needed. She liked having someone to take care of, which began earlier in life when taking care of her children. This role has been part of her identity and has been something that she has gotten used to over the years. Husbands had to take on more nontraditional gender roles (e.g., cooking, house cleaning) and they were not used to managing these household tasks. Husbands’ perceptions of their roles influenced how well they adapted and coped with caring for their spouse.

The perceived asynchrony and synchrony of the spouses’ roles influence how well they adapt to the dynamics and interactions within their relationship. Asynchronous life events can disrupt marital relationships; thus, having a spouse who is experiencing memory loss may be an added stress on the non-memory impaired spouse. How couples respond may be related to the level of impairment and their overall perceptions and beliefs about their relationship (Kulik, 2001). These aspects of marital relationships are influenced by changes and stability; however, they arise from a variety of factors.

As suggested by social exchange theory, spouses’ perceptions of reciprocity positively influenced their ability to develop effective coping strategies for caring for a spouse with cognitive impairments. Although reciprocity is not a mutual process, these

exchanges are not required to occur at the same point in time and do not necessarily involve giving and receiving the same things. The mixed emotions that were expressed by the spouses in this study have implications for social exchange theory in marriages that are challenged by MCI. Spouses described their emotions in context of the social exchange theory and overtly acknowledged elements of the theory (e.g., power, reciprocity). These relationships are bound by constant assessment and reassessment of each spouse's roles in the relationship. Future research should focus on the levels and intensity of these different factors to determine the most influential one on marital relationships. In addition, more exploration is needed on how a combination of mental and physical impairments from both members of the spousal dyad influences the dynamics and interactions within those marital relationships. Finally, future researchers should focus on mechanisms that lead spouses to assume the caregiver identity and attempt to manage their partner's everyday memory and behavior problems.

## CHAPTER V

### Conclusions

The spouses in this study expressed both change and stability within their marital relationships. The dynamics of the couples' interactions and communication style, expressions of intimacy, and division of household labor were influenced by the level of the elder's memory difficulties. The current definition of MCI suggests that there is no to minimal influence in the elders' daily and social lives (Petersen et al., 1999); yet, the elders in this study had difficulty in managing everyday activities as evidenced by changes in the decision-making process, household labor, and interactions with their spouses. This finding suggests that the existing definition is not sufficient to capture fully the daily characteristics of MCI; rather, there may be a progression of decline within MCI that involves gradual changes in abilities and social relationships that may go unnoticed in clinical evaluations.

Spouses expressed mixed emotions concerning the influence of MCI on both them as individuals and on their relationship. Their responses to whether and how their partners' memory loss influenced these emotions depended on the aspect of marital relationships (e.g., intimacy, interactions, perceived commitment). Indications of positive relationships were specifically evident within the aspect of socio-emotional intimacy (e.g., companionship, commitment, affection, emotional closeness). The spouses' use of "we" language demonstrated the idea that spouses felt emotionally connected to the elder (e.g., Kaplan, 2001; Kaplan, Ade-Ridder, Hennon, Brubaker, & Brubaker, 1995; Roberto, Gold, & Yorgason, 2004).

Spouses expressed more negative than positive emotional responses to the changes experienced by their spouse, and ultimately within their marital relationship. Perhaps this is because people first notice the negativity in a situation before recognizing the positive (Boerner, Reinhardt, Raykov, & Horowitz, 2004). Much of the social gerontology research focuses on negative relationship outcomes (e.g., burden, depression, stress) and concluded that the negativity weighs more heavily on social relationships than positive exchanges (Reinhardt, 2001). The spouses' comments about the negative aspects of their situation suggested that they were frustrated by the continual support they needed to provide for their spouse and the changes this brought to their lives.

As suggested by social exchange theory, spouses' perceptions of reciprocity positively influenced their ability to develop effective coping strategies for caring for a spouse with cognitive impairments. Although reciprocity is not a mutual process, these exchanges are not required to occur at the same point in time and do not necessarily involve giving and receiving the same things. The perceived asynchrony and synchrony of the spouses' roles influenced how well they adapt to the dynamics and interactions within their relationship. Asynchronous life events can disrupt marital relationships; thus, having a spouse who is experiencing memory loss may be an added stress on the non-memory impaired spouse. How couples respond may be related to the level of impairment and their overall perceptions and beliefs about their relationship (Kulik, 2001). These aspects of marital relationships are influenced by changes and stability; however, they arise from a variety of factors (e.g., elders' memory and behavior problems, health issues, unexpected role shifts). Future research should focus on the

levels and intensity of these different factors to determine the most influential one on marital relationships. In addition, more exploration is needed on how a combination of mental and physical impairments from both members of the spousal dyad influences the dynamics and interactions within those marital relationships.

### *Limitations*

Although the study findings shed new light on the lives of couples when one member of the dyad has mild memory loss, the limitations of the study need to be acknowledged. First, the small sample size precluded the use of statistical tests to compare data collection using the standardized measures. Only three of the five husbands completed the scales. Second, the interview questions specific to spousal relationships often were not directly asked, which made the interpretation more difficult. For example, a question regarding changes in physical intimacy was added to the interview protocol prior to the start of this study; however, due to the personal nature of the topic (e.g., sexual intimacy) and because the 6-month interviews were completed over the telephone, this question was not addressed. Third, it became evident that other factors (e.g., health, previous relationship dynamics) influenced the spouses' responses to the questions asked about their marital relationship. These factors were not examined in this study; however, future research in this area needs to take these contextual factors into consideration.

### *The Need for Future Research*

Researchers and clinicians need to pay close attention to the small, yet noticeable changes within the progression of MCI. Longitudinal research is needed to examine the influences that mild memory loss has on marital relationships over time. By

exploring marital relationships over time, researchers be able to identify more clearly the changes in the dynamics of these relationships (e.g., decision-making strategies, couple interaction) influenced by memory loss. This information is imperative for therapists, counselors, and support group leaders as they develop programs and interventions to address the individual and relationship needs of these couples.

Additional research also is needed to explore how couples define aspects of intimacy in their marital relationship. Researchers should examine the connections between couples' perceived socio-emotional intimacy and their real life situations (i.e., what is actually happening in the relationship). Because of the sensitivity of the topic, researchers need to be cognizant of the role that physical intimacy has on marital relationships where one spouse has cognitive impairments.

Finally, the influence of traditional gender roles needs to be further explored in the context of mild memory loss. Even in the mild stages of memory loss, couples have undergone major role transitions resulting from the elders' memory problems. Future research should examine family role shifts and transitions over time to determine the influences these changes have on the marital relationship. This research benefits clinicians and practitioners as they need to help family members attend to the unique stresses and strains of living with a spouse with mild memory loss. Clinicians would focus on making recommendations to spouses and couples regarding stress and coping strategies.

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Appendix A

Institutional Review Board Approval Form



Institutional Review Board

Dr. David M. Moore  
IRB (Human Subjects) Chair  
Assistant Vice President for Research Compliance  
CVM Phase II- Duckpond Dr., Blacksburg, VA 24061-0442  
Office: 540/231-4991; FAX: 540/231-6033  
email: moored@vt.edu

DATE: December 21, 2004

MEMORANDUM

TO: Karen A. Roberto Center for Gerontology 0426

FROM: David Moore 

SUBJECT: **IRB Exempt Approval:** "The Influences of Mild Cognitive Impairment (MCI) on Marital Relationship" IRB # 04-631

I have reviewed your request to the IRB for exemption for the above referenced project. I concur that the research falls within the exempt status. Approval is granted effective as of December 20, 2004.

Virginia Tech has an approved Federal Wide Assurance (FWA00000572, exp. 7/20/07) on file with OHRP, and its IRB Registration Number is IRB00000667.

cc: File  
Department Reviewer Michelle Stevenson 0416  
OSP 0170

## Appendix B

### Background Information – Primary Family Member

1. What is your 5-digit zip code? \_ \_ \_ \_ \_
1. What city and state is that?  
City \_\_\_\_\_ State \_\_\_\_\_
3. Please indicate your sex:
  1. Male
  2. Female
4. Which of the following best describes your ethnic background?
  1. Hispanic or Latino (includes persons of Cuban, Mexican, Puerto Rican, South American, Central American, or Spanish culture)
  2. Not Hispanic or Latino
5. Which of the following best describes your race? (mark all that apply)
  1. White/Caucasian
  2. Black or African American
  3. Native Hawaiian or other Pacific Islander
  4. American Indian or Alaska Native
  5. Asian
  6. Other (specify) \_\_\_\_\_
6. How old are you? \_\_\_\_\_ years
7. How many years of school did you complete?
  1. 1-8 (elementary school)
  2. 9-12 (high school or GED)
  3. Trade, vocational, or community college program
  4. 1-3 years of college
  5. College graduate
  6. Graduate school/professional school
8. What is your current marital status?
  1. Not married
  2. Married or partnered
9. For the majority of your life, what was your employment situation?
  1. Employed full-time
  2. Employed part-time
  3. Unemployed
  4. Homemaker

5. Other \_\_\_\_\_
10. If you were ever employed, what type of work did [do] you do most of the time?  
\_\_\_\_\_
11. Are you currently...  
1. Employed full-time for pay  
2. Employed part-time for pay  
3. Retired  
4. Unemployed  
5. A homemaker  
6. Something else (specify) \_\_\_\_\_
12. What is your relationship to the person who was evaluated at the Memory Clinic?  
Is that person your...  
1. Spouse or partner  
2. Parent or stepparent  
3. Brother or sister  
4. Other relative (specify) \_\_\_\_\_  
5. Friend  
6. Other (specify) \_\_\_\_\_
13. Where do you live in relation to the person who was evaluated at the Memory Clinic?  
1. In the same home or apartment building  
2. Not in the same home or apartment building  
how far is it from your home to their home? \_\_\_\_\_ miles
14. How important is religion in your life? Would you say that it is...  
1. Not at all important  
2. Somewhat unimportant  
3. Somewhat important  
4. Very important
15. Do you consider your religious affiliation to be...  
1. Protestant  
2. Catholic  
3. Jewish  
4. Muslim  
5. Other (specify) \_\_\_\_\_  
6. Not affiliated with a religion
16. How would you rate your overall health at the present time?  
1. Poor  
2. Fair  
3. Good  
4. Excellent

17. How much do any health problems stand in the way of your doing the things you want to do?
1. A great deal
  2. A little
  3. Not at all
18. What is the total monthly income before taxes for all adults in your household?
- |                                |                                 |
|--------------------------------|---------------------------------|
| 1. under \$1,000 per month     | (\$0 to \$11,999 per year)      |
| 2. \$1,000 - \$1,999 per month | (\$12,000 - \$23,999 per year)  |
| 3. \$2,000 - \$3,999 per month | (\$24,000 - \$47,999 per year)  |
| 4. \$4,000 - \$6,999 per month | (\$48,000 - \$83,999 per year)  |
| 5. \$7,000 - \$9,999 per month | (\$84,000 - \$119,999 per year) |
| 6. \$10,000 or more per month  | (\$120,000 or more per year)    |

## Appendix C

### Interview Guide for Spouses/Friends

Begin with genogram – create one for family/friends

1. What changes did you notice in [name of person evaluated at the Memory Clinic] that led to [her/his] visit to the Memory Clinic? When did these changes start? How long have you been dealing with minor and/or major difficulties with [name's] memory?
2. Did you go anywhere else before contacting the Memory Clinic? What happened? What was your reaction to that?
3. What is your reaction to the test results you got from the Memory Clinic? What is [name's] reaction? How about the rest of the family? Is there anyone who could be involved in dealing with this situation and is not?
4. I know that you are [name's] [wife/husband, daughter/son, friend, etc.], but besides that, what do you see as your role and relationship in helping [her/him] deal with the changes that are happening? How do you feel about that?
5. What are you doing to manage everyday life with [name]? Are you getting any outside help now that is different from help you got before? What kind? From whom?
6. Has [name's] doctor given you any information or suggestions for dealing with this situation? Have you found any helpful information elsewhere about memory loss in later life? What kind? Where did you get it? Is any of this helpful? In what ways?
7. Are you taking care of anyone else these days [child, parent, friend, etc.]? Do you get any help with that? From whom? Is that caregiving going to continue in the future?
8. What about your own physical and mental health these days—have you noticed any changes since [name's] situation began? What are you doing to make sure you stay as healthy as possible? Have you had to lessen or give up anything you found enjoyable before?
9. What do you think will happen with [name] in the future in terms of thinking and memory changes?
10. What kinds of information and assistance do you think [name] and you might need in the future? How comfortable would you feel about asking family members or friends for help? What about community agencies or senior services—do you know where to turn for help from them? Would you be willing to rely on them?
11. You might be faced with making some important decisions about [name] in the future [e.g., living arrangements, help with daily matters]. How have you gone about determining what to

do in the past if an important decision [about anything] came up? Who will be involved in making decisions about future plans for [name]? Is that different from before?

12. What suggestions would you give others about how to make living with memory loss easier?

## Appendix D

### **Interview Guide for Primary Family Members/Friends Six Month Follow-up telephone interview**

13. Overall, how have things been going with [name] since we talked?  
Have you noticed any specific changes in [name] over the past six months?
14. Since we last talked, have you gotten any information about memory loss that you have found helpful? What kind? Where did you get it?
15. When we first talked, you mentioned that [specific examples from first interview] to help manage everyday life with [name]. Are these strategies still working for you? Have you added any new strategies? Are you getting any help from anyone now that is different from help you got before? What kind? From whom?
16. Have your family or daily responsibilities changed since we talked? In what ways? How do you feel about that? Have there been any changes in what other individuals supporting [name] do since we talked? Individuals giving more support? Individuals giving less support? Who? Why?
17. And how are you doing these days (physically and mentally)—have you noticed any changes since we talked? [Use examples they mentioned in first interview, if any.] Have you had to decrease or give up anything you found enjoyable before?
18. Have you had any discussions with [name] or other family members or friends about what you might need to do in the future should his/her memory problems get worse? Have you found any specific information or individuals to be helpful in thinking about the future? What or who?

#### Spousal Questions

1. How long have you been married to this person?
2. Could you tell me a bit about the story of your relationship and marriage? For instance, over the years how would you describe the way you interact and communicate with one another? Have you shared household responsibilities? What kinds of activities do you enjoy together?
3. Has your marriage changed in any way since the memory problems first started? If so, in what ways and to what extent? Changes in conversation? marital roles? intimacy? household roles?

## Appendix E

### Revised Memory and Behavior Problems Checklist

	Statements	Did this happen last week? If not, circle no. If it did, circle yes and circle how you reacted →	If this happened, how much did it bother you? 0 = not at all 1 = a little 2 = moderately 3 = very much 4 = extremely				
1	Asking the same question over and over	no yes→	0	1	2	3	4
2	Trouble remembering recent events (e.g., news, TV)	no yes→	0	1	2	3	4
3	Trouble remembering significant past events	no yes→	0	1	2	3	4
4	Losing or misplacing things	no yes→	0	1	2	3	4
5	Forgetting what day it is	no yes→	0	1	2	3	4
6	Starting, but not finishing, things	no yes→	0	1	2	3	4
7	Difficulty concentrating on a task	no yes→	0	1	2	3	4
8	Destroying property	no yes→	0	1	2	3	4
9	Doing things that embarrass you	no yes→	0	1	2	3	4
10	Waking you or other family members at night	no yes→	0	1	2	3	4
11	Talking loudly and rapidly	no yes→	0	1	2	3	4
12	Appears anxious or worried	no yes→	0	1	2	3	4
13	Engaging in behavior that is potentially dangerous to self or others	no yes→	0	1	2	3	4
14	Threats to hurt oneself	no yes→	0	1	2	3	4
15	Threats to hurt others	no yes→	0	1	2	3	4
16	Aggressive to others verbally	no yes→	0	1	2	3	4
17	Appears sad or depressed	no yes→	0	1	2	3	4
18	Expressing feelings of hopelessness or sadness about the future (e.g., “Nothing worthwhile ever happens.” “I never do anything right.”)	no yes→	0	1	2	3	4
19	Crying and tearfulness	no yes→	0	1	2	3	4
20	Commenting about death of self or others (e.g., “Life isn’t worth living.” “I’d be better off dead.”)	no yes→	0	1	2	3	4
22	Comments about feeling worthless or being a burden to others	no yes→	0	1	2	3	4
23	Comments about feeling like a failure or about not having any worthwhile accomplishments in life	no yes→	0	1	2	3	4
24	Arguing, irritability, and/or complaining	no yes→	0	1	2	3	4

## Appendix F

### Zarit Burden Interview

Statements	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
1. Do you feel that because of the time you spend with your relative, you don't have enough time for yourself?	0	1	2	3	4
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3. Do you feel angry when you are around your relative?	0	1	2	3	4
4. Do you feel that your relative currently affects your relationship with family members and friends in a negative way?	0	1	2	3	4
5. Do you feel strained when you are around your relative?	0	1	2	3	4
6. Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9. Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11. Do you feel you should be doing more for your relative?	0	1	2	3	4
12. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

## Appendix G

### Center for Epidemiological Studies-Depression Scale

	<b>Statements</b>	<b>No (0)</b>	<b>Yes (1)</b>
1	During the past week were you bothered by things that don't usually bother you?	No	Yes
2	Did you not feel like eating or was your appetite poor?	No	Yes
3	Did you feel that you couldn't shake off the blues even with help from your family and friends?	No	Yes
4	Did you feel that you were as good as other people?	No	Yes
5	Did you have trouble keeping your mind on what you were doing?	No	Yes
6	Did you feel depressed?	No	Yes
7	Did you feel that everything you did was an effort?	No	Yes
8	Did you feel hopeful about the future?	No	Yes
9	Did you feel that your life had been a failure?	No	Yes
10	Did you feel fearful?	No	Yes
11	Was your sleep restless?	No	Yes
12	Were you happy?	No	Yes
13	Did you talk less than usual?	No	Yes
14	Did you feel lonely?	No	Yes
15	Were people unfriendly?	No	Yes
16	Did you enjoy life?	No	Yes
17	Did you have crying spells?	No	Yes
18	Did you feel sad?	No	Yes
19	Did you feel that people disliked you?	No	Yes
20	Did you feel that you just could not get going?	No	Yes

**Brianne L. Winston, B. A.**

3100 Richmond Lane, Apt. B

Blacksburg, VA 24060

540.998.9011

E-mail: [bwinston@vt.edu](mailto:bwinston@vt.edu)

**Education:**

**Present**

Pursuing a M.S. in Human Development  
Adult Development and Aging  
Virginia Polytechnic Institute & State University  
Expected Graduation Date: May 2005  
QCA: 3.70/4.0

**2003**

B.A. in Psychology  
Minor: Communication Studies  
West Virginia University  
GPA: 3.30/4.0

**Professional Experience:**

**Graduate Research Assistant**, Virginia Tech

Fall 2004-present

- Prepare dataset for use with SPSS software
- Create guidelines for imputation of missing data
- Conduct literature search on nature of missing data
- Supervisor: Rosemary Blieszner, Ph.D.; Jay A. Mancini, Ph.D.

**Graduate Research Assistant**, Virginia Tech, Center for Gerontology

Fall 2003-present, MCI project (support needs of families who are dealing with mild cognitive impairment-MCI)

- Conduct in-depth open-ended telephone interviews
- Transcribe interviews and analyze for themes
- Conduct literature searches on MCI
- Create codebook for quantitative scales
- Manage and enter data in SPSS
- Supervisor: Karen A. Roberto, Ph.D.

**Project Manager**, Virginia Tech, Adult Day Services

Spring 2004

- Active Together-PLUS walking/flexibility program for adults with dementia
- Constructed semester calendar
- Helped develop training materials for research team, including procedures, scales, protocols, schedules
- Trained research team members on data collection, data entry, and data cleaning
- Created codebook and datasets, cleaned, entered and analyzed data

- Supervisor: Shannon E. Jarrott, Ph.D.

**Graduate Research Assistant**, Virginia Tech, Adult Day Services (ADS)

Fall 2003-Spring 2004

- Worked one-on-one with ADS participants
- Worked on Active Together project at ADS
- Constructed semester calendars
- Completed observational data and interviews
- Entered, cleaned, and checked data in SPSS
- Created datasets
- Collaborated with staff and other students
- Supervisor: Shannon E. Jarrott, Ph.D.; Alison Galway, Ph.D.

**Publications:**

**Winston, B. L.**, Jarrott, S. E., & Rogers, S. D. (in press). Considerations for designing a walking and flexibility program for older adults with dementia. *Activities Directors' Quarterly*, 6.

**Professional Presentations:**

Wilcox, K. L., Roberto, K. A., Blieszner, R., & **Winston, B. L.** (2004, November). *Caregivers of persons with mild cognitive impairment: Information and support needs*. A poster presented at the annual meetings of the Gerontological Society of America, Washington, DC.

**Weaver, B. L.**, Roberto, K. A., Blieszner, R., & Wilcox, K. L. (2004, April). *Planning for the future: Family perspectives of the diagnosis of mild cognitive impairment (MCI)*. A paper presented at the meetings of the Southern Gerontological Society, Atlanta, GA.

Rogers, S., Gigliotti, C. M., Jarrott, S. E., & **Weaver, B. L.** (2004, April). *A group-based progressive strength training program for adults with dementia*. A workshop presented at the meetings of the Southern Gerontological Society, Atlanta, GA.

Kimble, K., Margrett, J. A., Marsiske, M., Moss, K. S., **Weaver, B. L.**, Miano, D., & Ruediger, E. L. (2002, November). *Problem solving skills and collaborative techniques of older unfamiliar dyads and married couples*. A poster presented at the annual meetings of the Gerontological Society of America, Boston, MA.

**Invited Presentations:**

**Weaver, B. L.**, 2004. April. *Results of the VADSA Marketing Survey*. Presentation at the meetings of the Virginia Adult Day Service Association, Richmond, VA.

Rogers, S., & **Weaver, B. L.** 2004. April. *A group-based progressive strength training program for adults with dementia*. Presentation at the meetings of the Virginia Adult Day Service Association, Richmond, VA.

Rogers, S., & Weaver, B. L. 2004. April. *A group-based progressive strength training program for adults with dementia*. Presentation at the South West Virginia Association of Activity Professional, Roanoke, VA.

### **Grants and Awards:**

- S. J. Ritchey Endowed Scholarship, 2005, from the Center for Gerontology, Virginia Tech: \$2,000
- Travel Grant, 2004, Presentation at the Gerontological Society of America, Washington, DC, from the Center for Gerontology, Virginia Tech: \$300
- Travel Grant, 2004, Presentation at the Southern Gerontological Society, Atlanta, GA, from the Center for Gerontology, Virginia Tech: \$350
- Travel Grant, 2002, Presentation at the Gerontological Society of America, Boston, MA, from the Undergraduate Enrichment Program, West Virginia University: \$500

### **Honor Societies and Professional Memberships:**

- Kappa Omicron Nu (Honor Society in Human Sciences), inducted Spring 2005
- Sigma Phi Omega (Honor Society in Gerontology), Treasurer, inducted Fall 2003
- Psi Chi Honor Society in Psychology, inducted Spring 2003
- Gerontological Society of America (GSA)
- Southern Gerontological Society (SGS)
- National Council for Family Relations (NCFR)

### **Service:**

- Sigma Phi Omega (Honor Society in Gerontology):
  - Treasurer 2003-present

### **Teaching Experience:**

Virginia Polytechnic Institute & State University:

HD 3004 Human Development II: Adult Development and Aging, “Sex and Aging”,  
Guest Lecturer, Fall 2004

HD 3314 Human Sexuality, “Sexuality in Later Life”, Guest Lecturer, Spring 2004

### **Trainings conducted:**

- Procedures for data collection, entry, and cleaning (AT-PLUS Research Team)

### **Trainings attended:**

- Institutional Review Board: Training in Human Subjects Protection
- National Safety Council, CPR and First Aid
- Atlas.ti, a qualitative software program