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Experience and Perspectives of Caregivers of Spouse with Mild Cognitive Impairment

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Abstract

The purpose of this paper is to describe commonalities of the lived experience of being a spouse caregiver of a person with mild cognitive impairment (MCI). The Colaizzi method of empirical phenomenology was used for inter-viewing and analyzing data obtained from 10 spouse caregivers of persons with MCI. Four major themes were found and labeled: (a) Putting the Puzzle Pieces Together-There Really is Something Wrong; (b) A Downward Spiral into a World of Silence; (c) Consequences to Caregivers of Living in a World of Silence; (d) Taking Charge of Care. The findings of this study provided rich data to guide interventions to help caregivers to improve their awareness of MCI, gain new information and skills to deal more effectively with and adjust to the caregiving of their spouse with MCI over the long-term.

Keywords

Caregiver perspectives; mild cognitive impairment; caregiving issues; stress; coping

INTRODUCTION

Most family caregiver studies have focused on family caregivers of persons with Alzheimer Disease (AD), but few studies have discussed family caregivers lived experience with their loved one with mild cognitive impairment (MCI). The transitional phase between healthy cognitive aging and dementia has been specified as MCI and has received much attention in recent years. MCI is a syndrome recognized as a cognitive decline greater than expected for an individual's age and educational level that interferes with functioning performance, but without other symptoms that would warrant a diagnosis of AD [1–4].

Mild cognitive impairment now is considered to be the predementia stage of AD, and it affects as many as 20% of older adults, nearly three times the number affected by dementia [5–8]. Persons diagnosed with MCI progress to AD at a high rate and display a conversion rate to dementia estimated to be 30% in 2.5 years [9] or from 60.5 % to 100% in 5 to 10 years [10, 11]. MCI is associated with significant morbidity; potential economic loss to the individual, family, and society; and frustration and distress in caregivers [12–15]. Many studies have found that MCI adversely affects the patient's cognitive, emotional, and behavioral functioning [16–19]. When married individuals develop MCI, they and their spouse caregivers must cope

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with uncertainty in dealing with symptoms, diagnosis, prognosis, the relationship with each other and with others in family, and the necessity of making future plans [15,19]. Depressive symptoms are common in elderly persons with MCI [20] and although some persons with MCI may not progress to AD, MCI can still result in a heavy personal burden that may have an effect on family caregivers, particularly spouse caregivers [12,16–18,21]. Spouse caregivers of persons with MCI are at the beginning stage of experiencing caregiver burden and lower quality in the marital relationship that could put them at risk of developing depression [12,15,21]. Recent studies found that the prevalence of depressed mood among 769 informal caregivers was 24.6% (95% confidence interval, 21.5–27.7) [22]. Understanding family caregivers lived experience with those persons who are at an increased risk of developing dementia is an important area in order to develop early and effective interventions. With a rapidly aging population, an increasing number of persons suffering from AD, and a shrinking caregiving cohort, suggests a critical need for interventions targeted at the beginning stage of MCI and at caregivers. At this early stage of cognitive decline, patients and their caregivers may have a critical window to develop important self-management skills that may prevent premature disability and disengagement. Developing self-management skills may improve the quality of life for both MCI patients and their caregivers, thereby saving billions of dollars for our society [13,15,23].

Over several decades many studies have extensively examined AD family caregiver burden and caregivers' experience of living with a spouse with AD [24–27], but few have described the experience of family caregivers of persons being diagnosed and living with MCI from the perspective of the spouse caregiver [28,29]. Understanding the process of caregiving for spouse family caregivers will be an important guide for future intervention. This report was part of a larger study that focused on family caregivers of persons with MCI by describing and analyzing their needs, concerns, decision-making process, self-management skills, relationships, and other factors that might influence their quality of life. In this paper we focus on the caregivers' experience of living with a spouse with MCI and describe, from an empirical phenomenological perspective, the commonalities of the experience of living with a spouse diagnosed with MCI. The results of this study may be useful to guide health care providers in creating supportive care interventions for caregivers and their spouses with MCI.

DESIGN AND METHODS

The design of this portion of the larger study was based on empirical phenomenology conducted through interviews with 11 spouse caregivers of persons with MCI. Empirical phenomenology is useful to describe the commonality of a phenomenon across experiences, in this case caregivers' experiences. This commonality is referred to as the essential structure of the experience, whereby the key factors common across caregivers are elucidated [30].

Sampling Methods

The purposive sample of 11 spouse caregivers of persons with MCI was recruited through the Alzheimer Disease Center Clinic in Indiana. The in-depth nature of the phenomenological interview method lends itself well to small sample sizes [31]. To determine the sample size for this study, we used the criterion of redundancy, which is met when themes identified during the ongoing data analysis are repeated and no new themes emerge.

Caregivers were English-speaking adults, aged 20 or older, and who had identified themselves as the primary caregiver for their spouse who had a medical diagnosis of MCI for at least 12 months. The diagnosis of MCI was made on the basis of clinical examination by a geriatric neurologist and/or neuropsychologist, using criteria consistent with the guidelines established by Petersen and colleagues [32]. To be included in the study, each caregiver had to be willing and able to describe his or her experience of living with their spouse diagnosed with MCI.

Data Collection

Approval for this study was obtained from the Institutional Review Board at Indiana University and informed consent was obtained prior to each interview. Data were collected from caregivers of the spouse with MCI in private rooms at the caregiver's home or in the hospital clinic. The open-ended interviews lasted 45 – 90 minutes and were conducted by one of two doctoral researchers. Efforts were made to reduce distractions or interruptions during the interviews. Caregivers were clearly eager to tell their story and were interviewed until they felt they had provided a full description of their experience. Each interview started with a broad data-generating question provided to caregivers at least 7 days prior to the interview: "Please tell me about your experiences that led up to your spouse was diagnosed with mild cognitive impairment and your experiences since your spouse being diagnosed." After caregivers described their experiences, additional descriptive questions were asked to understand their concerns and needs related to living with their spouses with mild cognitive impairment. Examples of additional questions are: "What are the things that have helped you deal with your spouse's mild cognitive impairment?" and "Please tell me about your concerns of living with your spouse since the diagnosis of MCI."

Data Analysis and Interpretation

Each interview was audiotaped. After the audiotapes were professionally transcribed, the data were analyzed using a step-by-step procedure adapted from Colaizzi's phenomenological method [33]. First, familiarity with the experience as a whole was gained by listening to the taped interviews and reading transcriptions for accuracy. Second, significant statements were identified, restated, and formulated into meanings by the first author. Third, the formulated meanings were discussed in meetings with research team members until consensus was reached by the research team. Fourth, themes were extracted from the formulated meanings. Fifth, extracted themes were organized into a hierarchy of themes across all caregiver data. Sixth, theme clusters and categories were examined and adjusted until consensus was reached during meetings of the research team. Seventh, an exhaustive narrative description of the experience that incorporated all themes was developed. Finally, the essential structure of the experience was developed.

Several strategies were used to ensure the validity, value, and credibility of the results. Prior to data collection, the interviewers conducted practice interviews and received peer critique to ensure a consistent approach to the interview process. Data analysis and validation were done as a team. For example, theme categories were derived separately by members of the research team then compared. The few discrepancies were discussed until 100% agreement was achieved.

FINDINGS

Sample

Of the 11 spouse caregivers of persons with MCI, interview data from only 10 (5 male and 5 female) were included in the data analysis, because we found that one female family caregiver's responses to the interview questions were frequently unrelated to questions asked and we could not discern any context to meaningfully tie her comments to the focus of our study. The age of the 10 participants ranged from 47 to 87 (mean 72, $SD = 11.22$) years and the time since spouse's diagnosis ranged from 1.5 to 4.5 years (mean = 2.5, $SD = 0.8$). All caregivers were Caucasian and married, with four in their second marriage. Seven had some college or higher education. All caregivers had a history of employment, with one still working in a full-time position, five working in part-time positions, and four retired. Most caregivers reported having some savings and having no financial burden. Two caregivers lived in retirement communities and 8 lived in their own house. Most of the caregivers ($n = 8$) reported that their household

income was just enough to meet their monthly needs or having some money left over, but two reported that they were not making enough money to meet their monthly needs.

Results

A total of 1618 significant statements about the experience of living with a spouse diagnosed with MCI were extracted from the data and analyzed. Table 1 shows the resulting four major theme categories and corresponding theme clusters. Each caregiver described the spouse's memory loss as a gradual and slow process with the following themes: (a) Putting the Puzzle Pieces Together- There Really is Something Wrong; (b) A Downward Spiral into a World of Silence; (c) Consequences of living in a World of Silence and Loss; (d) Taking Charge of Care.

The following is a detailed description of the themes related to each category. Pseudonyms are used throughout the results section.

PUTTING THE PUZZLE PIECES TOGETHER: THERE REALLY IS SOMETHING WRONG

Through a process of "putting the puzzle pieces together," caregivers gradually became aware that their spouse's cognitive impairment was long lasting and progressive. Susan: "Well, it is not something that came on all of a sudden. I mean it's just kind of a slowly developing process." As caregivers puzzled over the reality of memory problems, they eventually sought outside confirmation by seeking medical assessment. Beth: "I knew he was having memory problems years ago... For a long time I thought it was work and stress... I could see something was not quite right and it got down to where I eventually said, "John, maybe you should get tested." Through this gradual awareness process they eventually came to the conclusion that there really was something wrong.

Categories associated with this process of "Putting the Puzzle Pieces Together" included short-term memory decline, difficulty in engaging in familiar tasks, behavioral changes, emotional changes, and changes in social activity engagement. Short-term memory decline was one of the early signs of mild cognitive impairment. Beth: "He couldn't remember the things we just talked about 30 minutes ago. He has no hearing problem but that was the sign to me that he was not absorbing or retaining what he was hearing." Patient's struggles to remember dates, individuals' name, or appointments were commonly reported by caregivers. Caregivers realized that their spouses were having difficulty engaging in previously familiar tasks such as putting household items away, changing light bulbs, preparing dinner, or using "the to-do list" as usual. Joyce: "He realized that he couldn't do things that he easily had done before. Simple things like...[handyman activities] and then all at once he couldn't figure out how to do those anymore. It was very frustrating to him." As caregivers realized that their spouses were having difficulty in performing activities as usual, they gradually began to take over tasks and responsibilities. Beth: "He used to cook.... I have him do the dishes... It's hard for him to figure out where they... I'll just have to tell him where they go. Just leave them out and I'll put them away." It often took caregivers awhile to realize their spouse's financial management capabilities had lessened. David: "She sent several checks to unknown companies... she was cheated by some bad persons several times."

Caregivers also described their spouse's changes in behavior, emotional responses, and social activity engagement. Repeatedly asking questions was a common behavioral change. Joyce: "... he was forgetting more than what I thought was normal... Repeating things a lot, telling you the same things several times a day and there was some depression over this."

Emotional changes commonly found by caregivers included their spouses getting easily upset or angry and feeling irritable, worried, or sad as a consequence of having difficulty in

remembering or doing what used to be familiar tasks. Joyce: “He has become a bit more childish. Sometimes when he really can’t do things that he used to do before, he gets angry. And the anger that comes out, now that is hard to deal with.” Caregivers also realized that their spouse had difficulty in understanding the complex context or difficulty in following conversation while conversing with multiple parties and would then withdraw from social interaction. Joyce: “Sometimes it’s embarrassing because when there are people around he recedes back to his office. He is not comfortable being around large groups ... It is hard to carry on a conversation for him because people talk about politics, they talk about the war, they talk about everything and he doesn’t retain what he has heard.”

A DOWNWARD SPIRAL INTO A WORLD OF SILENCE

Caregivers experienced their own downward spiral into a world of silence as they put the pieces of the puzzle together. They described that their world was lost without any obvious warning signs. The characteristics of their loss were like a spiral in that the patients’ days of what seemed like normal aging increasingly became more markedly signs of MCI. Beth: “I didn’t know it was going on either. I was thinking that maybe he just doesn’t do that for me anymore or I don’t know. It was hard for me to detect that at the beginning.” Categories associated with this process of a downward spiral into a world of silence included (a) My Best Friend is Gone, (b) My World is Shrinking, and (c) Rollercoaster Distress.

Best Friend Is Gone

As memory worsened, caregivers experienced unwanted and uncontrollable changes in both the intimate and functional aspects of their relationship with the patients. Beth: “My best friend [husband] has been gone. He is part of me, but he is no longer the same person... He knows me better than anybody. I just don’t want to lose him ... I really miss him.”

The caregiver/patient dyads in the study had been married over 40 years and traditional roles were the norm. For wives, their husbands were most often the key decision maker. As the husbands’ executive functions declined, spouse caregivers had to take on decision-making roles for a wide range of issues. Phyllis: “...taking over someone’s life, making decisions for them, not telling them the whole truth every time, that was a terrible thing for me.”

Caregivers also experienced less effective communication and increasing misunderstanding and conflict with their spouse that was associated with the progression of memory problems and the spouse adjusting to the need for supervision. David: “She has that feeling that I’m against her and I’m not... The other day I said something to her about “Would you want me to help you with your meds?” “No! You’ve taken enough stuff away from me already.”

My World is Shrinking

Caregivers also experienced a shrinking world, including shrinking spaces, activities, finances, and social relationships. The aspects of the caregivers’ world that were shrinking included moving to more manageable housing, shifting to communities that were unfamiliar, compacting life routine, dwindling financial resources, and devastating relationship changes. Caregivers’ concerns for a manageable living space, and safe environment, as well as financial pressures, led them to reluctantly and often prematurely begin the process of selling their own home or business and moving into a smaller house, condo, or retirement community. Beth: “So we sold our business and in September we moved out of the house because it was too big. It was too much of a financial burden.” Although most participants carefully selected and planned for relocation, the process of adjustment to a new environment/community was challenging and stressful.

Daily life routines were shrinking as the spouse's condition resulted in decreased engagement in volunteer activities, leisure activities, and/or personal hobbies. Finances also often were shrinking because of patients' MCI-related early retirement or the need to meet the demands of caregiving. Beth: "Since this came on his memory, we had to get rid of our business. My husband was the owner of a business."

Caregivers also experienced shrinking social relationships with extended family members and friends. Beth: "Most people when they find out about this, they don't know how to ask about it. They don't understand he has memory problem... they don't realize how difficult it is."

Rollercoaster Distress

As caregivers became more aware of their spouse's condition, they intermittently experienced unpredictable periods of heightened emotional distress as they observed the consequences of their spouse's functional decline. The range of distressful emotions was linked to the situations and included shock, anger, guilt, anxiety, frustration, sadness, loneliness, helplessness, worry, and uncertainty. Beth: "I felt guilty and overwhelmed and I felt frustrated, people didn't understand." For example, caregivers described extreme frustration and anger when finding that someone was taking advantage of their spouse; they felt sad when seeing their loved one unable to do familiar tasks. Joyce: "It hurts (crying). I watch him try to do the simplest thing... And it is hard. It is hard to watch him, but there is nothing you can do, really."

Caregivers reached a tipping point in their ability to cope with the level of stress related to caregiving. Phyllis: "I've run out of the ability to cope and that's where I am right now." Caregivers also experienced emotional distress and frustration with family members and other significant friends who could not understand the situation. "Why can't you still do this? He looks fine!" In the midst of distress, caregivers looked for and held on to anything positive in the situation. David: "The diagnosis at that time was mild cognitive impairment, which it still is. A huge relief because still today there are many times that I ask myself (Am I just imagining this?)"

CONSEQUENCES TO CAREGIVERS OF LIVING IN A WORLD OF SILENCE

Caregivers experienced the consequences of living in a world of silence brought on by their spouse's memory loss. These included (a) Taking on Increased Obligations, (b) Decision-Making Challenge, and (c) High Cost to Quality of Life.

Taking on Increasing Obligations

As caregivers worked through the realization that the patient had gradually declined in cognitive and functional ability, they gradually took on more obligations to help the patients continue to be able to function for as long as possible. Joyce: "[providing care] is not something that I can't do for him. I want to take care of him as long as I can--and no matter what." Caregivers increasingly provided more detailed help to enable the patient to remain engaged in daily activities. Beth: "If I tell him or give him directions, he's fine. But left alone it's like he's floundering. He doesn't know what to do next. It was that way in the beginning, [I'd say] 'call me with questions' and he'd call me back with another question and I knew that was another thing that I thought [he would need help with]."

Decision-Making Challenges

Stepping in to make multiple decisions for the patient was challenging for caregivers, especially financial and legal decisions, when these were usually previously done by the patient. Phyllis: "... I did all the legal work, all the financial work, everything. I did it all. And so when I get discouraged sometimes I think you know the answer to the question why am I the person who

has to do this. The answer to that question is because I see what's happening and I'm capable of doing it. It's not easy. I don't want to do it but something has to be done."

High Cost to Quality of Life

Even at the stage of mild impairment, caregivers experienced a high cost to the quality of their life, including the quality of both married and personal life. Phyllis: "So it was very costly. It was costly to my marriage; it was costly personally to me because it made me feel lonely."

Taking Charge of Care

Caregivers gradually began to take charge as part of their long journey of caregiving. During this journey, they gradually identified their major needs and concerns and found the care strategies that worked best for them and their spouse.

Knowing Major Concerns and Needs

Caregivers' major concerns and needs included (a) information related to MCI (b) establishing effective communication skills, (c) developing caregiving skills, and (d) managing emotional distress for their spouse and for themselves.

Most caregivers reported that one of their major needs and concerns was searching for current information regarding the meaning of neuropsychological tests results at the diagnosis of MCI, especially related to prognosis. They also needed current information on pharmacological and non-pharmacological treatments. They expected the information to be provided by their health care providers. They also stated that being understood by the health providers was very important for them. Chris: "...it is really important to me to be able to talk, to understand, and listen [to health care providers]." They also had financial concerns associated with their spouse's increasing inability to manage finances, the costly new medications prescribed for their spouse, and the need to adjust their work situation to assure their spouse's safety in all settings.

They also had concerns and needs regarding establishing effective communication skills. These concerns were centered on the need to minimize misunderstanding and to retain or regain a trusting relationship. Beth: "At first he thought I was treating him like a little kid and so we had our battles. I'm just trying to help you... He knows that helps him and he doesn't take offense with me anymore." Caregivers experienced concerns about communicating using "white lies" because of the conflict between inner values and reality. Phyllis: "I did the preparation for our income taxes and sent them to our accountant because I would rather have him be angry with me for an hour about doing that than have him anxious and agitated for a week while he is trying to put those figures together unsuccessfully. So I have changed my definition of what is ethical behavior and I trust God understands that,... I can't tell him everything I've done and everything I'm going to do every time, every day. I can't do it. I just don't have the energy to do it or to cope with the results of it."

Caregivers also had a litany of caregiving skills they need to develop. These skills included: 1) managing their spouse's emotional distress. Joyce: "I think the hardest part for me is... I don't want to ever make him feel like he is less of a person, or I don't want to degrade him or embarrass him"; 2) assessing performance capacity, dealing with driving safety issues; 3) strategies to assure that their spouse was not being cheated when handling money. Matthew: "I really dread the day when she won't be able to have her checkbook...when she won't be able to drive... because I know how she's going to react and she's going to be very bitter, very bitter"; 4) making long-term care plans, Phyllis: "I've had a lot of family experience with dementia...I made the decision about when they needed to be in in-care."; 5) keeping their spouse involved with usual life routine activities, Beth: He doesn't know what to do for the

whole day and needs someone to guide him. My concern is how I'm going to keep him busy..."; and, 6) dealing with their spouse's behavior (e.g., repeating questions, sleeping problem, misplacing items).

Finding Care Strategies

All caregivers gradually found new strategies to cope with their spouse's functional deficits. These included: building a reminder system (e.g., using to do lists, calendars with large print, listing important contact phone numbers in visible places), engaging in some pleasurable activities together (e.g., attending Sunday service, eating out with good old friends), giving adequate time for their spouse to communicate, having a pet (dog) as company, moving into a retirement condo to allow more time to focus on their spouse, minimizing financial cheating by controlling unwanted mail, and being mindful of ways to manage their own emotional distress and health needs.

Most caregivers also recognized their stress was associated with patients' emotional distress and behavior problems (e.g., repeating questions, misplaced items, withdrawing from significant social events and others). Gradually, they developed new coping strategies in dealing with these stressors. Phyllis: "...I'm learning how on a daily basis to say I know what I need to do today. If I get to the end of the day and I need to, I go to a movie or just go to the grocery store and look at greeting cards..." Even when relocation was not a caregiver's preferred action, he or she began to realize and appreciate the good results from the relocation. Susan: "Since we moved here I don't have the responsibility of doing the outdoor work...I just feel sort of free...I feel very comfortable...."

ESSENTIAL STRUCTURE OF LIVING EXPERIENCE WITH SPOUSE WITH MILD COGNITIVE IMPAIRMENT

The essential structure of the experience of being a spouse caregiver of a person with mild cognitive impairment (MCI) began as a long process of trying to put the puzzle pieces together to get a picture of the spouse's progression of memory impairment. As part of the process, caregivers became aware of their spouse's memory decline through the declines in their spouse's abilities, behavioral and emotional changes, and social interactions. This awareness and the actual multiple changes in the patient and the responses of others led caregivers to a downward spiral into a world of silence. That world was characterized as shrinking and accompanied by great waves of distress, loneliness, lost relationships, and diminished interactions. As consequences of living in a world of silence, caregivers took on increasing obligations, were challenged to make many decisions alone, and paid for these choices in diminished quality of life for themselves. Gradually, they made their way through this world to begin to take charge of what they could, gaining knowledge about each concern and identifying specific strategies to address them.

DISCUSSION

An examination of each of the major theme categories and comparison of the findings with existing literature is presented in the discussion section. The limitations of this study and clinical implications for practice are also presented.

Putting the Puzzle Pieces Together

Becoming aware of the spouse's mild memory problem and putting the puzzle pieces together was a lengthy and confusing process. Even though caregivers had previous in-depth understanding of their spouse, they initially lacked awareness and knowledge of what was happening to their spouse. All caregivers experienced difficulty in sorting out the differences

between the signs of memory decline, normal aging, and working stress. Findings from our study of caregivers of MCI patients are similar to the pattern of becoming aware of the memory problem that was in the literature for AD caregivers at the early stage [26]. The literature indicates that caregivers try to define and sort out their spouse's unusual behaviors, research the conclusion that their spouse's behaviors are not normal and are problematic, and figure out what to do next. The specific troublesome behaviors in our study are similar to those found in a recent study that described caregivers' concerns that patients were "asking the same questions over and over again," "losing or misplacing things," and had "trouble remembering recent things" [21], as well as "getting angry easily" and "were less engaged in social activities than usual."

A Downward Spiral into a World of Silence

Even at this earliest stage of MCI, the caregivers experienced behavioral stressors similar to those in the literature. This indicates that there is a variety of behaviors exhibited as part of MCI impairment that are both frequently occurring and distressing to spousal caregivers [12, 21]. Still at this stage of cognitive impairment, caregivers gradually experienced loss of intimacy in their relationship, loss of communication with spouse, loss of the hoped-for future, and loss of social and recreational interactions. These losses are similar to those found in caregiving studies of those persons in the advanced stage of cognitive impairment [21,22,34–36]. Caregivers in this study experienced similar emotional responses to patients' behaviors as did caregivers of patients with dementia, and these responses were robust predictors of distress outcomes for family caregivers [12,37–42]. Our study found that caregivers experienced a wide range of distressful emotions such as shock, anger, guilt, anxiety, frustration, sadness, loneliness, helplessness, and uncertainty that were associated with spouses' symptoms of cognitive impairment, behavior changes, and functional deficits that were similar to those of caregivers of patients with AD [28,42–45]. However, they also felt relieved that their spouse was not diagnosed with AD and that the deterioration in signs and symptoms of cognitive impairment would only gradually occur over several years [12].

Consequences to Caregivers of Living in a World of Silence

Similar to previous studies, our findings showed that caregivers first realized the changes in their spouse's behaviors and performance capability, then followed with a reflection on the changes that had occurred [26,46,47]. The caregivers gradually recognized their quality of life was significantly affected by their spouse's cognitive impairment, but at the same time, they gradually began to take on roles and activities that were usually performed by their spouse as they experienced an increased sense of obligation to take care of their spouse. Most of the caregivers met the challenges in making decisions for the patients. Some decision-making required new knowledge and skills, or professional assistance, such as selling property (house or husband's company), relocating to retirement housing, filing taxes, and selecting treatment.

Taking Charge of Care

Previous studies also support our findings that caregivers need information regarding the diagnosis and treatment of MCI. These studies indicate that brief information and support-oriented therapies are associated with modest reductions in caregiver emotional distress [29, 48,49]. Therefore, providing brief information and early support-oriented therapies for caregivers and patients at the early stages of MCI may minimize later emotional distress.

Some recent caregiving intervention studies found that caregiving skill-building treatment interventions were more effective than standard care in reducing caregiver distress in dealing with the care receiver's agitated symptoms over time, but were equally effective to standard care in improving caregiver management skills over time [50,51]. Since MCI patients are more aware of their own deficits and experience fewer specific troublesome behaviors than AD

patients, providing early intervention on caregiving knowledge and skill-building may help build caregiving confidence to prevent or minimize patients' problem behaviors and obtain better outcomes with less cost over time.

Compared to previous studies in caring for persons with dementia [52–54], the caregivers of this study reported fewer and less multifaceted safety concerns than AD caregivers. With the need to focus on fewer and less multifaceted safety concerns, interventions to improve safety may be more easily implemented and learned by caregivers in the early stages of MCI, when the issues are less complex. In the literature, there are no reliable measures of driving capability and little is known about how to manage driving cessation for MCI patients. Previous studies reported that the driving issues most difficult to manage were AD patients who were not aware of the need to make changes [54]. Since MCI patients are more aware of their decision, it might be an optimum opportunity for caregivers and patients to make balanced and mutually agreed-upon decisions relative to driving that are based on patients' strengths and limitations at this stage of cognitive impairment. They might also discuss future scenarios when driving would not be safe and this could make it easier for the caregiver to have the resolve to tell the patient to stop driving when that time comes.

STRENGTHS, LIMITATIONS, AND IMPLICATIONS

The strengths of this study include a nearly equal gender representation of spouse caregivers and the fact that the participants were living independently in various settings such as their own home or a retirement community. Limitations in this study are a lack of diversity in socioeconomic status and ethnicity and a lack of a longitudinal perspective on patients' progress. Future studies should include more minority subjects from varied socioeconomic status and multiple interview time points along the various stages of caregiving memory loss progresses. Our study showed that there is a critical need to develop an early intervention that can help MCI patient-caregiver dyads modify behavior, compensate for deficits, and minimize negative outcomes from conflicts associated with those deficits. The perspectives provided by the caregivers in this study are rich in implications for finding interventions to help caregivers gain awareness, information, and learn skills to more effectively deal with and adjust to caring for their MCI spouse over time.

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Table 1**The Lived Experience of Having A Spouse with MCI**

Major Theme	Theme Cluster
Putting the puzzle pieces together: There really is something wrong	<ul style="list-style-type: none"> a. Short-term memory declining b. Difficulty in engaging in some familiar tasks c. Behavioral changes d. Emotional changes e. Changes in social activity engagement
A downward spiral into a world of silence	<ul style="list-style-type: none"> a. Best friend is gone b. My world is shrinking c. Rollercoaster distress
Consequences to caregivers of living in a world of silence	<ul style="list-style-type: none"> a. Taking on increasing obligation b. Decision-making challenge c. High cost to quality of life
Taking charge of care	<ul style="list-style-type: none"> a. Knowing major needs and concerns b. Finding care strategies