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Caring for an individual with mild cognitive impairment: A qualitative perspective of health-related quality of life from caregivers

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Abstract

Objectives.—Current literature highlights several negative sequelae for caregivers of individuals with Mild Cognitive Impairment (MCI), but little is known regarding the effect that caring for an individual with MCI has on health-related quality of life (HRQOL). The primary purpose of this paper was to identify the most important aspects of HRQOL related to caring for an individual with MCI.

Methods.—Six focus groups were conducted with caregivers of individuals with MCI (n=32). Focus group discussions were transcribed verbatim, and a qualitative frequency analysis approach was used to analyze the data.

Results.—Qualitative frequency analysis revealed that caregivers of individuals with MCI most frequently discussed their social health, including changes in their social roles and an increased need for social support (51.2% of the total discussion). This was followed by mental health concerns (37.9%) centering on anger, frustration, and a need for patience in the caregiving role, as well as caregiver-specific anxiety. Other discussion topics included physical health (10.0%), and the impact that stress and burden have on medical health, and caregivers' cognitive health (0.9%) including memory problems in relation to caregiver strain, sleep disruption, and cognitive fatigue.

Conclusions.—Findings illustrate the multiple domains of HRQOL that are affected in individuals providing care for someone with MCI. Moreover, findings highlight the need for extending support services to MCI caregivers, a group that is generally overlooked and are typically not offered support services due to the "less severe" nature of an MCI diagnosis.

Keywords

Mild Cognitive Impairment; Cognitive Disorders; Caregiver; Quality of Life; Qualitative Research; Focus Groups

While extensive literature exists on caregiving for individuals diagnosed with Alzheimer's disease (Dunkin & Anderson-Hanley, 1998; Etters, Goodall, & Harrison, 2008; Georges, Jansen, Jackson, Meyrieux, Sadowska, & Selmes, 2008; Pinquart & Sorensen, 2007; Richard Schulz, O'Brien, Bookwala, & Fleissner, 1995; Waite A, 2004), less is known about those who care for individuals diagnosed with Mild Cognitive Impairment (MCI), often an intermediate phase between normal cognitive decline and dementia (Petersen, 2004a; Petersen Rc & et al., 2001). The role of caring for someone with MCI is inherently different than the role of caring for individuals with dementia. For example, while research would suggest that there are negative sequelae (such as emotional strain, disruption of daily and task-related responsibilities, lifestyle constraints, and sleep disturbance) for caring for someone with MCI (Blieszner & Roberto, 2010; Fisher, Franks, Plassman, Brown, Potter, Llewellyn et al., 2011; Garand, Dew, Eazor, DeKosky, & Reynolds, 2005; Hayashi, Terada, Nagao, Ikeda, Shindo, Oshima et al., 2013; Ikeda, Terada, Oshima, Hayashi, Okahisa, Takaki et al., 2015; Kamiya, Sakurai, Ogama, Maki, & Toba, 2014; Kelleher, Tolea, & Galvin, 2016; Lee, Heo, Yoon, Chang, Lee, Rhee et al., 2014; Paradise, McCade, Hickie, Diamond, Lewis, & Naismith, 2015; Roberto, McCann, & Blieszner, 2013; Ryan, Weldon, Persad, Heidebrink, Barbas, & Giordani, 2012; Seeher, Low, Reppermund, & Brodaty, 2013; Springate & Tremont, 2013; Szeto, Mowszowski, Gilat, Walton, Naismith, & Lewis, 2016; Trivedi, Subramanyam, Pinto, & Gambhire, 2013), factors such as the uncertainty about the development of a dementing diagnosis (e.g., Alzheimer's disease), uncertainty regarding the clinical course and prognosis of MCI, and the potential for a long disease course pose a unique set of challenges for the caregivers of these individuals. Regardless of this evidence, caregivers of individuals with MCI remain a significantly underserved population (Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008; Fisher et al., 2011).

Little is known about how caregiving specifically affects the health related quality of life (HRQOL) of those who care for individuals with MCI. HRQOL is a multidimensional construct reflecting the impact that a disease/disability or its treatment has on mental, physical, and social well-being (Cella, 1995). When available, spouses tend to serve as the

first line of defense for individuals with MCI (Savla, Granger, Roberto, Davey, Blieszner, & Gwazdauskas, 2013), , putting themselves at increased risk for decreased HRQOL and other deleterious health effects (Gaugler, Davey, Pearlin, & Zarit, 2000; R. Schulz & Beach, 1999; R. Schulz & Sherwood, 2008; R. Schulz, Visintainer, & Williamson, 1990; Vitaliano, Scanlan, Krenz, Schwartz, & Marcovina, 1996; Vitaliano, Schulz, Kiecolt-Glaser, & Grant, 1997; Vitaliano, Zhang, & Scanlan, 2003). In fact, research on spousal caregivers of individuals with MCI has demonstrated that even though the stressors may be considered minor, these can have a negative impact on allostatic processes of the Hypothalamic-Pituitary-Adrenal (HPA) axis and the Autonomic Nervous System (ANS; Savla, Roberto, Blieszner, Cox, & Gwazdauskas, 2011). Thus, it is important for us to better understand exactly how caring for an individual with MCI may affect the HRQOL of the person providing care.

The purpose of the current study is to identify and characterize salient domains of HRQOL that are important to caregivers of individuals with MCI. Findings can help identify the most appropriate areas for clinical interventions (including mental health and respite), and may provide a basis for elucidating the differences between caregivers of those with MCI and those caring for someone who is further along the dementia spectrum (i.e., caring for an individual with Alzheimer's disease). Findings can also provide complimentary information for researchers and clinicians looking to better understand the stress process framework for caregivers (Pearlin, Mullan, Semple, & Skaff, 1990) and the stress and coping model (Lazarus & Folkman, 1984), or the idea that minor hassles may have small, but cumulative effects that can result in more serious stress reactions (including problems with mental and physical health).

Method

Participants

To identify relevant HRQOL themes, six focus groups were conducted with caregivers of individuals with MCI (n = 32 participants). These groups were conducted at the University of Michigan. Caregivers were recruited through established neurology (87.5%) and neuropsychology clinics (3.1%) via the patient who was receiving care through online medical record data capture systems (Hanauer, Mei, Law, Khanna, & Zheng, 2015), and participant registries from the Michigan Alzheimer's Disease Center (MADC; 3%). Inclusion criteria required that caregiver participants be at least 18 years of age, able to read and understand English, and currently providing care to an individual with a medical diagnosis of MCI. A diagnosis of MCI was provided by neurologists or neuropsychologists in the above clinics who generally use Peterson et al criteria and includes a reported change in cognitive functioning by either the patient or others (e.g., family member, physician) in the context of no global cognitive impairments and no substantial changes in adaptive functioning (Petersen, 2004b). Within the MADC, MCI diagnoses were confirmed via medical records using the same Petersen criteria and to ensure that criteria set by the National Institute of Neurological and Communicative Disorders and Stroke—Alzheimer's Disease and Related Disorders Association were met (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984; Morris, Weintraub, Chui, Cummings, Decarli, Ferris et al.,

2006). The MADC also uses a consensus research process whereby three study clinicians must agree on diagnosis. Caregivers were excluded if there was an indication that the patient's condition had progressed to Alzheimer's disease (or another related dementia diagnosis) since their last clinic appointment or when records were reviewed. Caregivers were also excluded if medical records suggested a possible non-neurodegenerative cause of cognitive decline. All data collection was done in accordance with the University of Michigan institutional review board, and informed consent was obtained prior to participation in this study.

Data Collection and Analysis

All focus groups followed a semi-structured guide developed to assess caregiver HRQOL (see Appendix). Groups began with open-ended questions posed by group facilitators and progressed to more specific questions targeting the caregivers' perception of their own physical, mental, social, and cognitive HRQOL. Focus group sessions were approximately two hours in length and were led by two doctoral-level clinical psychologists (N.C. and K.R.). Observation and note-taking of each group was conducted by gerontologist / caregiving expert (C.S.) and research associates (M.B. and K.A.). Audio recordings of each focus group were transcribed verbatim and de-identified, and NVivo 10.0 (QSR International Pty Ltd., 2012) was used to analyze the data.

A qualitative frequency analysis approach was used to analyze the data. This approach follows the coding blueprint outlined by Kisala and Tulsy (2010), which includes the development of a domain framework, open and axial coding, selective coding, and descriptive analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1998). This approach has been used extensively in work examining HRQOL in other clinical conditions (Carlozzi, Brickell, French, Sander, Kratz, Tulsy et al., 2016; Carlozzi, Fyffe, Morin, Byrne, Tulsy, Victorson et al., 2013; Carlozzi, Kratz, Sander, Chiaravalloti, Brickell, Lange et al., 2015; Carlozzi & Ready, 2011; Carlozzi & Tulsy, 2013; Carlozzi, Tulsy, & Kisala, 2011; Kratz, Sander, Brickell, Lange, & Carlozzi, 2015). Specifically, two independent investigators reviewed all transcripts to identify major content areas to develop a list of initial subdomains. These subdomains were grouped according to the multidimensional HRQOL theoretical framework developed by the World Health Organization, including physical, mental, and social health. All transcripts were then reviewed using an inductive process to expand the framework to include MCI specific domains/subdomains eventually creating a "codebook" for each domain (N.C., K.R., and C.S.). Codebook development was further informed by a comprehensive review of the MCI-related caregiver literature. The codebooks were refined and expanded to include emerging themes until saturation occurred. Codebooks were finalized by elaborating definitions of themes and outlining rules of inclusion/exclusion (see Appendix).

Next, two independent coders (K.A., A.A., and/or M.B.) were required to achieve > 80% overall agreement on 25 statements in order to establish inter-rater reliability. Then, two raters would code the first transcript together to ensure reliability. Subsequently, the remaining transcripts would be coded by the raters individually; all instances of disagreement were then reconciled with the consultation of a third individual (K.R. or A.A.)

when necessary. Frequency tables denoting the number of times each response was made according to each codebook highlight the overall findings from these groups.

Results

On average, caregivers were 69.41 years of age ($SD = 7.87$). Participants were predominantly female (80%) and Caucasian (97%). The majority of participants were spouses of an individual with MCI (80%), followed by adult children (17 %), or other relative (3%). The average time of providing care was 3.95 years ($SD = 3.36$; range 0.5 to 15 years) with 71.4% of patients being 18 months or more post MCI diagnosis. Individuals with MCI were 75.8 years of age on average ($SD=6.3$), had 16.1 years of education ($SD=3.0$), and 56.3% were male. The majority of these individuals were diagnosed by a neurologist and confirmed by neuropsychological testing (84.4%); average mental status scores at the time of diagnosis were 25.7 ($SD=2.4$) for the Mini Mental Status Examination (Folstein, Folstein, & McHugh, 1975) and 24.8 ($SD=2.4$) for the Montreal Cognitive Assessment (Nasreddine, Phillips, Bedirian, Charbonneau, Whitehead, Collin et al., 2005). The average time since diagnosis (until the focus group date) for these individuals was 5.9 months ($SD = 5.0$), 62.5% were diagnosed with amnesic MCI and 12.5% with non-amnesic MCI (type of MCI was unavailable for 25% of the sample).

Qualitative Frequency Analysis

Saturation was achieved by the fourth focus group, after which no new nodes were added to the codebook and additional revisions were not necessary. Two additional groups were conducted in accordance with established methods (Kisala & Tulsy, 2010) to maximize the stability/robustness of the frequency analysis. Frequency percentages are based on the number of times a topic was coded in relation to the total number of items coded, reflecting the relative importance of each of the domains discussed.

A summary of the themes emergent in the focus groups included caregiver social health (51.2%), mental health (37.9%), physical health (10.0%), and cognitive health (0.9%); See Table 1.

Social health.

Across all focus groups, the most frequently discussed HRQOL topic was caregiver social health (51.2% of the total discussion). This discussion focused largely on social role changes experienced by the caregivers (“Because I feel like I’m a parent now; he’s not my husband, I’m his parent, his mother”) as well as the caregivers’ perceptions of inadequate family support (“I get no help from either [his] brother or sister”), informational support (“I have no real solid information or advice to go on about how to proceed as some sort of caretaker for her”), and instrumental support (“I don’t have anybody that I could just easily bring in”). Caregivers also discussed community support (“I think support groups are wonderful”), as well as concerns related to a loss of companionship (“He used talk about politics, about anything we could talk about. I’ve lost my best friend”), changes in vocation (“I don’t work a whole lot”), financial strain (“Will it leave me impoverished, having to take care of him?”), and a lack of emotional support (“I don’t have anybody to talk to about it”). Perceptions of

stigma related to how others see the individual with the MCI (“Once they have a diagnosis, they think, “Oh, well, he can’t do this; he can’t do that”), as well as how these perceptions influence the caregivers’ social roles (“Well, they [the person with the MCI] can’t quite keep up so we’ll just go along and not include... [the person with the MCI and their caregiver/spouse in our future social plans]”) were also important topics of discussion.

Mental health.

Mental health was the second most frequent topic of discussion, accounting for 37.9% of the conversation. Participants spoke most often about their own increased anger, frustration and lack of patience (“The situation that I’m in, I would say being a caregiver I’m frustrated all the time, I need to learn to have more patience”). This was followed by caregiver-specific anxiety, which included caregiver uncertainty (“I don’t know what to say to him and what not to say sometimes because I never know whether that’s going to set him off”), worry about the future (“But what worries me the most I guess is what’s in the future”), and anxiety about driving (“But now I’m afraid to have him drive home in all the traffic”). Caregivers also discussed several other HRQOL themes including depression, general anxiety, and positive emotions. In addition, caregiver strain/stress (i.e., feelings of being overwhelmed and stressed when interacting with the person they care for; “there are times when I feel overwhelmed”) and feelings of being trapped (i.e., being uncomfortable or anxious when leaving the individual with MCI alone; “and yet I’m worried about leaving him alone for more than four or six hours”) were also raised as concerns.

Physical health.

Physical health was the third most frequently discussed HRQOL domain (10.0% of the discussion). Caregivers commonly identified concerns with medical care/medications; the majority of this discussion focused on the discussion of needing to take antidepressant medication themselves (“So that’s the only way I can deal with it, too. I have to take medicine”). In addition, caregivers also discussed health behavior including conversations about exercise (“yoga really helps”) and taking time to focus on their own physical needs and health care (“and I find that I’m doing better just getting enough rest”). Sleep was also a common topic of discussion (“And I was still having a really hard time sleeping”), followed by concerns about fatigue (“I was exhausted”) and pain (“I’ve got aches and pains”).

Cognitive health.

Finally, less than 1% of the discussion focused on cognitive health concerns amongst the caregivers themselves. Caregivers expressed concerns about their own memory problems, especially in relation to caregiver stress/strain, sleep disruption, and general fatigue (“I mean, the level of fatigue I have and the level of stress I’m feeling any point in time is what affects my memory”).

Discussion

Findings from this study highlight how providing care for someone with MCI can impact multiple aspects of the caregiver’s HRQOL. Specifically, caregivers of individuals with MCI discussed how their caring role was associated with changes in social, mental and physical

health. Even though these caregivers were caring for someone with mild cognitive deficits who were not showing substantial changes in functioning, the emergent themes were reminiscent of findings in caregivers of more severe dementia conditions (Kuo, Huang, Hsu, & Shyu, 2014; Trigg, Jones, Knapp, King, Lacey, & Groups, 2015; Yikilkan, Aypak, & Gorpelioglu, 2014). This is also consistent with previous work in MCI that would suggest that minor hassles might have a cumulative negative affects on caregiver HRQOL (Savla et al., 2013; Savla et al., 2011). This is striking given that caregivers at this stage are generally overlooked and are typically not offered support services due to the relatively mild nature of the person with MCI's condition. With regard to social health concerns, the discussion was focused on how providing care was associated with changes in their social role (with both spouses and children caregivers having to take on more responsibilities), and the barriers encountered with the often increasing need for social support (family, informational, and instrumental support). These themes were consistent with literature examining caregivers for more severe dementia populations which demonstrate decreased social satisfaction and decreased social interactions (D'Onofrio, Sancarolo, Addante, Ciccone, Cascavilla, Paris et al., 2015; Yikilkan et al., 2014), as well as changes in social roles, reflecting their transition to a greater overseer role (Karlin, Bell, & Noah, 2001; Mioshi, Bristow, Cook, & Hodges, 2009; Pruchno & Resch, 1989; Yektatalab, Sharif, Kaveh, Fallahi Khoshknab, & Petramfar, 2013).

Caregivers frequently discussed how providing care for an individual with MCI has affected their own mental health. A common topic of discussion was anger and frustration; caregivers expressed frustration about how much longer it took their care partner to do things, or mentally process things, and how there was a need to exhibit much more patience with their care-partner. This is not surprising given prior research highlighting the need for increased patience and tolerance when caring for an individual with dementia (Cheng, Mak, Lau, Ng, & Lam, 2015). In addition, caregivers frequently described feelings of anxiety associated with the unknown nature and course of MCI, as well as a more general anxiety related to the increase in responsibilities. Again, these issues have been highlighted in both qualitative and quantitative work examining caregivers in other dementia populations (Boltz, Chippendale, Resnick, & Galvin, 2015; Joling, van Marwijk, Veldhuijzen, van der Horst, Scheltens, Smit et al., 2015; Mannion, 2008; Mioshi et al., 2009; Ostojic, Vidovic, Bacekovic, Brecic, & Jukic, 2014; Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015; Santos, Sousa, Simoes-Neto, Nogueira, Belfort, Torres et al., 2014; Yikilkan et al., 2014).

Similar to other caregiver populations, stress and burden were also common complaints of these MCI caregivers (Gronning, Kristiansen, Dyre, Rahmani, Gyllenborg, & Hogh, 2013; Jones, Romeo, Trigg, Knapp, Sato, King et al., 2015; Karlin et al., 2001; Mioshi et al., 2009; Ornstein, Gaugler, Zahodne, & Stern, 2014; Sallim et al., 2015; Santos et al., 2014; Zarit, Todd, & Zarit, 1986). Discussion also focused on how this emotional stress and strain affected physical health, including caregivers' need for medical treatment for depression themselves and exacerbation of physical pain (Mannion, 2008), as well as difficulties with sleep and fatigue; findings which are consistent with the general caregiving literature (Cupidi, Realmuto, Lo Coco, Cinturino, Talamanca, Arnao et al., 2012; Lee et al., 2014; Mannion, 2008; Peng, Lorenz, & Chang, 2015; von Kanel, Mausbach, Ancoli-Israel, Dimsdale, Mills, Patterson et al., 2012). In addition, caregivers often described neglecting

their personal health needs in order to prioritize their care-partner's needs. Although neglect of self-care is common to other caregiver populations (Richardson, Lee, Berg-Weger, & Grossberg, 2013), it was sobering to hear this common theme among caregivers of individuals with less advanced or less extensive cognitive impairment. Overall, these findings are consistent with what we might expect among caregivers of patients with dementia, both at the earlier and late stages of the dementing condition. These similarities are noteworthy, especially given that many of the patient-related predictors of caregiving burden (e.g., frailty/disability, loss of function, global cognitive impairment, and neuropsychiatric symptoms; Matsumoto, Ikeda, Fukuhara, Shinagawa, Ishikawa, Mori et al., 2007; Pinquart & Sorensen, 2005; Rinaldi, Spazzafumo, Mastriforti, Mattioli, Marvardi, Polidori et al., 2005; Rocca, Leotta, Liffredo, Mingrone, Sigauco, Capellero et al., 2010) are not prevalent in individuals' with MCI and by definition of MCI criteria, these individuals are still considered to be quite independent and functional.

That being said, regardless of the "mild" or "minor" stressors these caregivers may encounter, these stressors are having a negative effect on their HRQOL. Furthermore, there is also objective data to suggest that these relatively "minor" stressors have real physiological effects that may ultimately lead to poorer health outcomes (Savla et al., 2011; 2013). In addition, while some caregivers clearly indicated that the person they were caring did not have functional problems, their descriptions of the behavioral challenges that their care-recipient experienced were occasionally contradictory to these statements. Given that labeling is common in other mental health conditions, it would not be surprising to find that misattributions of functional problems in MCI may be commonplace. Such labeling problems might also add to these cumulative effects.

Moreover, the reported lack of information about MCI and its potential progression (or not) to AD, as well as a lack of supportive counselling available to these individuals only serves to perpetuate these negative effects on HRQOL for these caregivers. Thus, we believe that future work should focus on educating both the caregiver and care-recipient about what MCI is, how it may or may not lead to more advanced dementia, and the different symptoms that might suggest potential decline and warrant further follow-up. While this may be seemingly controversial in a condition that may or may not be progressive, it is not unlike other conditions where you are told to contact the doctor if your fever worsens above a certain point or if you notice changes in your mood or appetite after beginning a certain medication. Furthermore, given that MCI diagnoses are typically made based on a single neurocognitive assessment relative to previous functioning, it may be possible that an MCI diagnosis is given in error due to normal variations in test performance, general measurement error, or unreliable patient and/or family report. Thus, regardless of whether these symptoms are or are not indicative of a worsening condition, they can help provide the care-recipients with information about when to pursue additional follow-up.

While this study highlights the diverse ways in which providing care for an individual with MCI can affect HRQOL, there are study limitations to consider. First, the majority of our care-partners were Caucasian and spouses, thus it is unclear how the findings generalize to other caregiver relationships and races. In addition, we did not control for interviewer bias in our study. We also used a qualitative approach that was developed to quantify discussion

topics; this approach relies on frequency counts to determine the relative importance of topic area. This approach depicts valuable patterns, but may not yield the same pattern of findings as more traditional qualitative analysis approaches which rely more heavily on coder interpretation (e.g., narrative analysis, latent content analysis). In addition, while this work highlights the different aspects of HRQOL that are affected in these caregivers, it does not address the underlying behaviors and relationships that are leading to these negative changes in HRQOL. For example, there is some evidence from other studies that unpleasant marital interactions (Savla et al., 2013) and behavioral changes (i.e., sundowning; Savla et al., 2011) are stressful interactions that are associated with physiological burden. This work is relatively new, and thus a better understanding across the diverse aspects of HRQOL that are affected in these caregivers is needed. Furthermore, while we compare findings to the general AD caregiving literature, we do not have data to directly compare these caregivers of individuals with MCI to caregivers of individuals with AD. Thus, future work is needed to identify and quantify these differences.

This is one of the first qualitative studies, to our knowledge, to focus explicitly on how providing care for individuals with MCI affects HRQOL and highlights the impact that caring for someone with MCI has on a caregiver. Furthermore, these findings are generally consistent with, although likely less severe than, research in caregivers of individuals with Alzheimer's disease. Such commonalities suggest that these caregivers are at increased risk for adverse outcomes and would likely benefit from early MCI-specific mental health interventions, education, and support.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix

MCI Caregiver Focus Group Guide

Opening Statement

Thank you for agreeing to participate in this research project. I'm Dr. Noelle Carlozzi and I will be the facilitator for this discussion, and this is Dr. Kelly Ryan, my co-facilitator. Dr. Ryan and I are working together to learn more about "quality of life" in caregivers of individuals with mild cognitive impairment (MCI) in order to develop a new survey. One of our current projects is to develop a questionnaire about what researchers refer to as the "quality of life" of caregivers of individuals with MCI. By "quality of life", we mean the symptoms, problems, and concerns, as well as any gains, fulfillment, or joys that caregivers have as a direct or indirect result of caring for their loved one with MCI. The best way to

develop a questionnaire like this is to talk with the caregivers and learn about their experiences caring for their loved ones with MCI. Once we've developed this questionnaire it will be used by identify caregiver needs and develop appropriate interventions to assess these needs.

We've asked you to meet with us here today in what researchers call a "focus group". A "focus group" is a group of people that researchers get together to talk about some topic, so the researchers can learn what the people think or know about that topic. In a focus group it's really important that you say what you think. There are no right or wrong answers. We want to know what you think. If you would like to add to an idea, or if you have an idea that's different from someone else's, feel free to jump in. You don't need to wait for me to call on you to talk, but only one person should talk at a time. We appreciate that you have taken the time to participate in our group today.

We will be tape recording this session to be sure we don't miss anything you say, but we won't be keeping track of who said what, so anything you say is anonymous. That is, your responses will not be linked to your name. Please speak up and talk one at a time so we can hear you clearly when the recording is transcribed. We only have 90 minutes, so it will be my and Dr. Ryan's job to will keep us moving along. In focus groups we want the discussion to be among you, because it is your thoughts and opinions that we want to hear. We want you to talk with each other and express our opinions. Our job as facilitators will be to keep the discussion moving along and to keep the discussion focused on topics we want to know about, so please don't be offended if one of us redirects the discussion; we would like the interaction to flow among you.

I. Introduction & Ice-Breaker

For example: "Let's go around the room and introduce ourselves. Tell us your first name and why you decided to participate in the focus group."

II. Free List Exercise on Quality of Life

Sample Questions:

- What do you think of when I say the phrase "quality of life" as it relates to your experiences as a caregiver?
- What kinds of things/what areas of your life are affected because you are the caregiver for a loved one with MCI?

Probes: *Emotions (moods and feelings)? Physical abilities and limitations (sleep difficulties and muscle tension)? Social interactions (relationships with family, friends, peers, coworkers)? Caregiver burden?*

If additional questions are needed to elicit responses:

- In what ways has your life changed (for better or worse) since you assumed responsibilities as a caregiver for a loved one with MCI.
- In what ways is your life different from others who are not caring for an individual with MCI?

Probes: *Emotions (moods and feelings)? Physical abilities and limitations (sleep difficulties and muscle tension)? Social interactions (relationships with family, friends, peers, coworkers)? Caregiver burden?*

NOTE: Emotional, Physical, and Social Health should be discussed.

Additional Questions:

- What types of services/interventions would be useful for you as an individual providing care for someone with MCI?
- What types of things did you wish you had known before you started providing care for someone with an MCI?

III. Closure

“Did these exercises bring to mind any other issues that affect your quality of life?”

“Thinking back to our discussion, is there anything else that you would like to comment on now?”

“Thank you again for your participation. Your input is invaluable because no one else can tell us what issues are most important for caregivers of individuals with MCI. The quality of life questionnaire that we are creating will be very important in the improving the quality of life of individuals with MCI and their caregivers.”

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Table 1

Health-Related Quality of Life (HRQOL) Themes Generated Among Caregivers of Individuals with a Mild Cognitive Impairment (MCI)

HRQOL Domain and Subdomains	Example Quotation	Overall Thematic Breakdown
<u>SOCIAL HEALTH</u>		(51.2%)
Caregiver Social Role Change	"Sometimes it's more like being a parent or a teacher than a wife"	30.8
Family Involvement	"I'm lucky that I've got 4 daughters who will do anything for us"	18.2
Informational and Instrumental Support	"I don't have the kind of information I want"	16.9
Community Life/Recreation	"I started going to this support group"	7.6
Companionship	"It's like your soul mate is somebody you never even knew anymore."	6.0
Vocation	"Well, I retired ..., and my mom took a fall the second part of that year. And I taught classes. So I finished that, and then I thought, 'Well, here I go. This is my retirement. I'll just keep caregiving.'"	4.6
Finances	"I worry about money because I know a couple of people who are in memory care, full care, and it's a lot of money every year"	4.4
Emotional Support	"One other thing that helps me is I have a close friend that I can talk to"	4.4
Stigma	"And sometimes I don't think they understand that she has something wrong with her, and they think that she's just doing it for attention sometimes"	3.2
<u>MENTAL HEALTH</u>		(37.9%)
Anger	"You wanna scream"	20.7
Caregiver-Specific Anxiety	"I guess I have a fear of what's coming, what's going to happen next"	19.9
Depression	"And I would have these times where I'd sit down and I'd cry"	13.9
General Anxiety	"I have horrible anxiety"	11.4
Positive Emotions	"it does help me feel a little bit more confident"	8.5
Caregiver Strain/Stress	"Some days I feel like, 'Oh, boy. I have to take care of everything around here now.'"	8.1
Feeling Trapped	"I find I'm very uncomfortable leaving him for very long"	6.0
<u>PHYSICAL HEALTH</u>		(10.0%)
Medical Care/Medication	"I have to take depression medicine every day"	33.8
Health Behaviors	"I don't think I got any physical effects so far, but it's because I'm taking really good care of myself"	15.2
Sleep	"I have a lot of trouble sleeping"	10.3
Fatigue	"I just had no energy. Physically, I was completely worn out."	8.3
Pain	"and it will be so bad that sometimes I can barely walk"	4.1
<u>COGNITIVE HEALTH</u>	"I don't remember anything anymore"	(0.9%)

Note. Percentages for Domains reflect the total percentage of comments related to this specific domain (Domain percentages should sum to 100 with rounding); percentages within each Subdomains reflect the percentage of comments within each Domain (should sum to ~100).