Published in final edited form as:

Res Gerontol Nurs. 2012 July ; 5(3): 195–206. doi:10.3928/19404921-20120605-04.

Illness Representations in Older Adults with Mild Cognitive Impairment

Feng Lin, PhD RN [Research Associate],
School of Nursing, University of Rochester Medical Center HWH 2W128 601 Elmwood Ave, Rochester NY 14642

Carey E. Gleason, PhD MS [Assistant Professor], and
School of Medicine and Public Health, University of Wisconsin-Madison, Madison WI

Susan M. Heidrich, PhD RN [Professor Emeritus]
Helen Denne Schulte Professor School of Nursing, University of Wisconsin-Madison, Madison WI

Abstract

Little is known about patients' understanding of a diagnosis of Mild Cognitive Impairment (MCI). The purpose of this cross-sectional descriptive study was to describe beliefs about MCI in persons diagnosed with MCI and examine correlates (demographic and health) of those beliefs. Thirty persons diagnosed with MCI completed the Illness Perception Questionnaire-MCI (IPQ-MCI), measuring eight domains of beliefs about MCI, and one scale of emotional distress. Five of them also participated in a 15-minute cognitive interview to explore responses to the IPQ-MCI. Participants correctly identified symptoms related to MCI; generally attributed MCI to aging, heredity, and abnormal brain changes; and believed MCI to be chronic, predictable, and controllable, causing little emotional distress. However, there were no consistent beliefs regarding the negative consequences of MCI or whether MCI was understandable. There were few significant correlates of beliefs. Persons with MCI are able to report their beliefs about their illness suggesting that misconceptions and gaps in knowledge can be identified and addressed with nursing interventions.

Keywords

Mild Cognitive Impairment; illness representation; cognitive disorder

Introduction

Mild cognitive impairment (MCI) is diagnosed when there is a mild decline in either single or multiple cognitive domains — such as memory, executive functioning, attention, or visuospatial abilities — while global cognition and basic activities of daily living remain intact (Gauthier et al., 2006). The estimated prevalence of MCI varies from 2.8% to 23.4% in several nationwide surveys of older (> age 65) adults (Ganguli, 2006; Larrieu et al., 2002). Persons with MCI may eventually develop Alzheimer's (AD) or other dementias, but many do not (Gauthier et al., 2006; Petersen, 2007). With the aging of the population, there will be approximately 11 to 16 million Americans with AD by 2050, which suggests the number of persons with MCI will also be increasing (Alzheimer's Association, 2011).

Correspondence to: Feng Lin.

Office phone: 585-276-6002 Fax: 585-273-1270 vankee_lin@urmc.rochester.edu.

Most people diagnosed with MCI live in the community. Recent evidence suggests that persons with MCI have more difficulty than their healthy counterparts in everyday functioning that involves cognitive abilities including driving, telephone use, finding belongings, grocery shopping, medication management, and handling finances (Aretouli & Brandt, 2009; Wadley, Okonkwo, Crowe, & Ross-Meadows, 2008). Even subtle declines in everyday functioning have been associated with decreased independence and safety, increased caregiver burden (Gauthier et al., 2006), a reduced chance of reverting to normal cognitive status, and increased likelihood of developing dementia in both clinic- and community-based MCI cohorts (Farias, Mungas, Reed, Harvey, & DeCarli, 2009; Purser, Fillenbaum, Pieper, & Wallace, 2005). Persons diagnosed with MCI face uncertainty, particularly related to illness progression. A review of forty-one cohort studies suggest that, over 3 to 10 years, an average of 32 % of person with MCI progress to dementia, while the rest either remain stable with MCI or revert to normal cognition (Mitchell & Shiri-Feshki, 2009).

In contrast to Alzheimer's disease (AD), there is little public recognition or understanding of MCI nor much available public information that would inform beliefs about MCI (Blay & Piza Peluso Ede, 2008; Roberts & Connell, 2000; Suhr & Kinkela, 2007; Werner, 2003) even though being diagnosed with MCI is becoming more prevalent (Roberts, Karlawish, Uhlmann, Petersen, & Green, 2009). It is important to understand the beliefs persons with MCI have about the diagnosis since those beliefs may motivate behaviors in response to the diagnosis. Such knowledge is necessary to develop and provide appropriate information and support services to individuals with MCI and their families.

One way to conceptualize a person's experience of illness is Leventhal's Common Sense Model (CSM) (Leventhal, Nerenz, & Steele, 1984). The CSM proposes that an individual's beliefs about an illness or health threat are an organized set of cognitive representations that can influence coping behaviors (e.g., self-care, adherence to treatment) that, in turn, have an impact on health outcomes (Leventhal et al., 1984). Five dimensions of representations have consistently been found in empirical research (see Figure 1): identity, cause, time-line, consequences, and cure/control. Identity refers to the symptoms one ascribes to a health problem. Cause refers to an individual's beliefs about the origin of the health problem. Timeline is beliefs about the temporal nature (e.g., acute, chronic, or cyclic) of the health problem. Consequences are beliefs about the impact of the health problem on one's life. Cure/control refers to people's beliefs about whether they can prevent, cure or control their health problem (Leventhal, Brissette, & Leventhal, 2003). Moss-Morris (2002) added two new domains: coherence and emotional representations. Coherence is one's belief that the health problem is understandable or makes sense. Emotional representations capture how the health problem affects the person emotionally. A meta-analysis of research based on the CSM across 23 chronic illnesses (Hagger & Orbell, 2003) indicates support for a number of the hypothesized relationships. In general, people with more positive representations of the illness (e.g., more controllability) tend to engage in problem-focused coping and report higher levels of psychological well-being. More negative representations (e.g., more symptoms endorsed to a health problem, chronic timeline, worse consequences) are related to more emotion-focused coping and worse health outcomes. These relationships, however, differ among different illnesses. It is not known how these relationships will hold in people with MCI.

The CSM has not been used to investigate beliefs about MCI. However, five studies (Frank et al., 2006; Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008; Lingler et al., 2006; Lu, Haase, & Farran, 2007; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008) have described some beliefs about MCI. Four were qualitative studies (Frank et al., 2006; Joosten-Weyn Banningh et al., 2008; Lingler et al., 2006; Lu et al., 2007), and one was descriptive study with 46 subjects (McIlvane et al., 2008). The qualitative studies were consistent in finding that patients with MCI reported experiencing cognitive symptoms (e.g., memory impairment) and somatic symptoms (e.g., headaches, fatigue), considered MCI to be chronic or were uncertain about the future course of MCI, and described negative consequences of MCI (e.g., losses in their lives, being treated differently, and stigma). Those studies differed, however, in findings related to emotional distress as a result of MCI and perceptions of whether MCI could be controlled or slowed. In McIlvane's descriptive study (M age = 77.3 yrs), 40% of the sample reported that their likelihood of conversion to Alzheimer's disease was zero, and 76% of the sample reported that the disease process was controllable through practical strategies (e.g., by staying optimistic, through mental or physical exercise). Lingler et al. (2006) discussed that the meaning people assigned to their diagnosis of MCI suggested they were actively involved in both cognitive and emotional processing of information about their illness. She suggested that the CSM may be a useful framework for evaluating the structure, correlates, and consequences of beliefs about MCI.

This study was conducted to systematically assess the dimensions of representations of MCI as proposed by the CSM. The dimensions include: identity, cause, timeline, consequences, cure/control, coherence, and emotional distress. The specific aims were to (1) describe representations of MCI in persons with MCI, and (2) examine the relationships between domains of representations and demographic information and health history.

Method

Design

A cross-sectional descriptive study was conducted.

Sample

Thirty persons diagnosed with MCI participated in this study. They were recruited from memory clinics at a University Hospital and a Veterans Administration Hospital in the Midwest. Inclusion criteria were: (1) aged 60 or older, (2) English-speaking, (3) diagnosed with MCI for at least 3 months, (4) community-dwelling, (5) capacity to provide informed consent and willingness to participate, and (6) having a care partner who was either living with or in contact with the patient at least once per week and who could accompany the participant to the interview. Care partners were an Institutional Review Board requirement for research projects conducted at the Memory Clinics at either the University Hospital or Veterans Administration Hospital.

To be eligible, participants had to be diagnosed with MCI using the Mayo Clinic diagnostic criteria (Petersen, 2004), which defines MCI as impairment (1 to 2 SD below the population norms) in one or more cognitive domains, but not meeting the criteria of AD or other dementia, and patient or care-partner reported decline in instrumental activities of daily living (IADL). Participant assessments in the two clinics at the time of diagnosis were the same, including a family history interview, physical examination, standard laboratory tests, and the Geriatric Depression Scale (GDS) (Sheikh & Yesavage, 1986). Neuropsychological testing included the Mini-Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), the Neurobehavioral Cognitive Status Examination (Cognistat) (Northern California Neurobehavioral Group, 2001), the CERAD Word List Learning Test (Morris et al., 1993), Clock Draw test (Sunderland et al., 1989), Trail Making Test A and B (Reitan, 1958), and Animal Fluency Task (Spreen & Strauss, 1998). Final diagnosis was by consensus of the geriatricians, neuropsychologists, and a social worker. At the time of diagnosis, a clinician met with each patient and his/her care partner after the consensus meeting to discuss and clarify the diagnosis of MCI and the risks of progression. Description of the diagnostic procedure can also be found in other publications recruiting patients with MCI from the same clinics (e.g., Ries et al. 2007). Diagnosis of MCI was confirmed by the physicians from the two clinics within one month of participants' recruitment into the study.

Procedure

The study was approved by University of Wisconsin Health Sciences Institutional Review Board and the Veterans Administration Hospital Research and Development committee. Clinicians approached all eligible patients and obtained permission for the first author to contact them. Contacts were made via phone or at a follow-up clinic appointment. An appointment was made for a research study visit at the hospitals. At that appointment, the study was explained and written informed consent was obtained from both participants and their care partners. Participants then completed all self-report questionnaires. Care partners were instructed that they could assist participants in completing the demographic and health information. However, since the purpose of this study was to understand the participants' *own* experiences after the diagnosis of MCI, the care partners were asked to limit their assistance with the participant's completion of the remainder of the questionnaires to helping with reading the items. Care partners assisted only two out of 30 participants (one with frailty, the other with vision difficulty) by reading the items on the questionnaire to them. They did not assist the participants in responding to the items. Participants spent an average of 25 minutes ($SD = 7$, range: 13 – 43) completing the questionnaires.

Of the 32 patients approached by clinicians and investigators, one declined because of impaired hearing and another due to a scheduling problem. Thirty subjects (24 males and 6 females) provided informed consent to participate in this study. A subsample of five participants (the first five who agreed) took part in a cognitive interview (described in Measurements). Given participants' memory deficits and the burden of a return visit, cognitive interviews were conducted immediately after participants finished completing the study questionnaires.

Measurements

Representations of MCI—

The Illness Perception Questionnaire–MCI (IPQ-MCI) was used to measure participants' beliefs about MCI. The IPQ-MCI was developed by modifying the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), which is a generic measure of illness beliefs that can be adapted for use with various illnesses and health threats. The original IPQ-R has been used to examine representations across a number of illnesses and has demonstrated good reliability (Cronbach's α ranges 0.67 – 0.86 across subscales) and validity (Moss-Morris et al., 2002).

A brief Illness Perception Questionnaire (Brief IPQ) is available (Broadbent, Petrie, Main, & Weinman, 2006). It consists of nine items, and each item is a single-item measure of a domain of illness representations, that has some good psychometric properties. It is designed to provide rapid assessment of illness perceptions. It has been recommended for use in very ill or frail populations, in clinical settings, in studies with a large number of questionnaires and substantial participant burden, or in longitudinal studies with repeated measures. We chose the original IPQ-R for a number of reasons. First, we were interested in describing the content of persons' representations, which would not be possible with the single-item measures. Second, we wished to assess the feasibility of older persons with MCI completing the longer scales as pilot data for a larger scale study. Third, because in future research we wish to use multivariate models to test the relationships proposed by the CSM, we wanted to avoid single-item measures if possible.

To modify the original IPQ-R, we replaced the word "illness" in the original scale with "diagnosis of MCI." Several items from each subscale were modified to tap into the unique characteristics of MCI and its symptoms (described below). All modifications were based on a review of the literature and expert review by geriatricians and neuropsychologists in the ADRC and VA memory clinics. The IPQ-MCI scale included 8 subscales: *Identity* (26 items), *Consequences* (12 items), *Chronic timeline* (5 items), *Cyclic timeline* (4 items), *Personal control* (6 items), *Treatment control* (5 items), *Coherence* (5 items), and *Causes* (25 items).

For the *Identity* subscale, we expanded the list of somatic symptoms in the IPQ-R to include 14 cognitive symptoms typical in MCI. It is important to note that, for the identity subscale, participants were asked whether they believed each symptom on the list was related to MCI, not whether the participant actually experienced that symptom.

For the *Consequences* subscale, four MCI-related items – "MCI will progress to dementia," "MCI makes me feel stigmatized," "MCI makes me lose self-confidence," and "MCI makes me lose my independence" – were added. For *Chronic timeline*, one item, "My MCI will get worse over time," was added. For *Treatment control*, one item, "There are practical ways to manage the symptoms of MCI," was added. For the *Causes* subscale, four items were added to include both risk and protective factors for MCI identified in the literature, including "Lack of antioxidants, such as Vitamin C, " "Abnormal changes in the brain," " Chronic illness (e.g. Diabetes, High blood pressure)," and "Obesity" (Scarmeas et al., 2009; Tervo et al., 2004).

For the Consequence, Chronic Timeline, Cyclical Timeline, Personal Control, Treatment Control, and *Coherence* subscales, participants responded to each item on a 1 (strongly disagree) to 5 (strongly agree) scale. The mean of each subscale was computed with higher scores indicating worse consequences, more chronic and unpredictable timeline, more control over the illness by personal abilities or effective treatments, and less perceived understanding of MCI. The *Identity* and *Causes* subscales have dichotomous responses (yes or no). The total number of symptoms and causes were calculated.

Because the original *Emotional representation* subscale of the IPQ-R did not tap a number of the emotional responses to MCI described by MCI patients in the qualitative research reviewed, emotional distress was measured with a slightly revised version of the Profile of Mood States—Short form (POMS) (Shacham, 1983). The POMS is one of the most widely used mood inventories. It assesses multiple dimensions of mood: tension, depression, anger, vigor, fatigue, and confusion. The POMS has been validated in older adults and is easy to complete (Kaye et al., 1988). In qualitative studies of patients' emotional responses to a diagnosis of MCI, some reported emotions that may be unique to MCI, included, "relative relief in the absence of a dementia diagnosis" and "fear of loss self" (Lingler et al., 2006). Two items – "relief" and "scared" – were added to the scale. The "relief" item was reverse-coded. Two items in the original scale—"forgetful" and "unable to concentrate"—were deleted because they are symptoms of MCI. The "vigor" subscale was not used because it does not capture emotional distress. The final scale included 31 items. Participants responded to each item on a 0 (not at all) to 4 (extremely) scale. A mean score of each subscale was computed, and a sum of those mean scores was used, with higher scores indicating more emotional distress. Reliability (Cronbach's alpha) of the modified POMS in this sample was .93.

Cognitive Interview—Cognitive interviews are useful in questionnaire development to examine whether or not answers to questionnaires are valid (i.e., that participants understand and can respond to the intended meaning of the items). Cognitive interviews have been used successfully in cognitively impaired older people (Wright & Holliday, 2007). The recommended sample size for cognitive interviews is between 5 and 15 (Willis, 2005). The goal for this small study was to interview 5 participants. For this study, seven items representative of each dimension of representation were selected for the interview. During the interviews, the investigator showed participants their answers to each item and asked them to explain why they answered in that way. All interviews were tape-recorded and transcribed verbatim. Investigators compared the participant's ratings with his/her explanations for the given response. If the explanations were consistent with the ratings across all seven items, we considered the participant's answers to be valid.

Demographic and health history information—Demographic information included age (in years), gender, race/ethnicity (five categories), education (in years), retirement status (retired vs. still employed), marital status (married vs. not married), living arrangement (alone vs. with others), and family annual income (< $10,000, $10,000 – $50,000, $50,000 – $99,999, $100,000 – $199,999, or ≥ $200,000).

Health history was measured with the Wisconsin Longitudinal Study (Form F) (Hauser, 2005). Participants identified whether they had been told by a healthcare provider that they had any of 20 health problems, and the number of health problems was summed. We also collected data on global cognition measured by the Mini Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), level of depression measured by the 15-item Geriatric Depression Scale (GDS) (Sheikh & Yesavage, 1986), and months since diagnosis of MCI.

Data analysis

SPSS Version16.0 was used in the data analysis. Summary statistics were computed for demographic information and health history. Descriptive statistics were used to describe representations. Pearson's correlation coefficients were used to examine the relationships between IPQ-MCI subscales and demographic information and health history. The Mann-Whitney U-test was used to examine whether participants’ representations differed by gender, marital status married vs. not married), living arrangement (living alone vs. living with others), and family annual income (< $50,000 vs. ≥ $50,000)

Results

Sample characteristics

The average age was 76.97 years. Participants were somewhat highly educated, and 29 out of 30 were Caucasian, which reflected the local population. The mean GDS score was 1.57, which reflects a low level of depressive symptoms. Participants reported an average of 5 chronic illnesses; the most frequently reported were high blood pressure (63%), high cholesterol (60%), and arthritis (43%). Seventeen participants (56.7%) had been diagnosed with MCI within one year, 10 (33.3%) between 1 and 5 years, and 3(10%) more than 5 years (see Table 1).

Representations of MCI

Psychometric and descriptive data for each domain of representation are presented separately below. For the *Identity* and *Cause* subscales, reliability and item-total correlations are not reported because these two scales are dichotomous or count variables rather than Likert scales.

Responses to the *Identity* subscale are in Table 2. Participants endorsed an average of 9 symptoms ($SD = 6.56$) that they believed were related to MCI. The most frequently endorsed symptoms (by 50% of participants or more) were cognition-related, including, memory (e.g., forgetting appointments) and language (e.g., trouble finding words). The least frequently endorsed symptoms (10% or less) were somatic symptoms common in old age, for example, stiff joints and hearing loss (see Table 2).

Responses to the *Cause* subscale are in Table 3. Participants endorsed an average of 4 causes (*SD* = 3.24) of MCI. The four most frequently endorsed causes of MCI were aging, heredity, abnormal brain change, and stress. The remaining items were endorsed by 20% or fewer of the sample, including some that are possible risk factors for MCI (e.g., chronic illness/ diabetes, high blood pressure).

Table 4 reports responses to the *Consequences* and *Coherence* Subscales. For the *Consequences* subscale, item-total correlations ranged from .29 – .67, with 9 of the 10 items > .30. Item-total correlations of the four new items ranged from .31 – .60. The reliability (Cronbach's alpha) was .84. For the *Coherence* subscale (5 items), item-total correlations ranged from .45 – .80. There were no new items. Reliability (alpha) was .84.

Inspection of the mean scores and distribution of responses to the *Consequence* and *Coherence* subscales indicated numerous bimodal distributions. Thus, mean scores on these subscales were not informative. Because of this, we computed the frequency of participants responding to each item in three categories: “disagree or strongly disagree,” “agree or strongly agree,” and “neither agree nor disagree”. For *Consequences*, over half of participants agreed that “MCI is a serious condition,” “MCI has major consequences for my life,” and “MCI causes difficulties for those who close to me.” Consistent with these responses, over half disagreed with the statement, “MCI does not have much effect on my life.” On the other hand, about half of participants disagreed with the statements, “MCI makes me feel stigmatized,” and “MCI makes me lose my independence.” Fifty percent were uncertain whether “MCI strongly affects the way others see or treat me,” and “MCI will progress to dementia.” The remaining Consequences items were mixed.

For *Coherence*, 60% disagreed with the statement, “MCI doesn't make any sense to me.” For the remaining *Coherence* items, almost equal numbers of participants agreed or disagreed with those statements.

The Chronic timeline, Cyclic timeline, Personal control, and *Treatment control,* scalescores were normally distributed. For *Chronic timeline* (7 items), item-total correlations ranged from .09 – .75. Six of 7 items were > .30, including the one new item (.59). Reliability (alpha) was .69. For *Cyclic timeline* (4 items), item-total correlations ranged from .29 – .61. Three of 4 items were > .30, and there were no new items. Reliability (alpha) was .62. For *Personal Control* (5 items), item-total correlations ranged from .24 – .74. Four of 5 items were > .30; there were no new items. Reliability (alpha) was .80. For *Treatment Control* (6 items), item-total correlations ranged from .35 – .74. One new item = .35. Reliability (alpha) was .81. Mean scores indicated that participants perceived that MCI will be long-lasting (*Chronic timeline*: *M* = 3.51, *SD* = 0.63), but somewhat predictable (*Cyclical timeline*: *M* = 2.74, *SD* = 0.64) and controllable through personal strategies (*Personal control*: *M* = 3.31, *SD* = 0.62) and medical treatment (*Treatment control*: *M* = 3.44, *SD* = 0.54). They also reported a low level of emotional distress on the modified POMS scale (*M* = 7.13, *SD* = 2.66).

Relationships among domains

Correlations among the domains of representations suggested that representations were generally independent with the majority of r's ranging from .01 – .20 (see Table 5). Significant correlations included, more negative consequences of MCI were significantly related a more chronic timeline ($r = .44$, $p = .016$) and more emotional distress ($r = .40$, $p = .027$). A more chronic timeline was related to less personal control ($r = -.44$, $p = .016$) and more emotional distress ($r = .51$, $p = .004$). Personal control was strongly correlated with treatment control ($r = .75$, $p < .001$).

A few demographic and health history variables were significantly related to representations. Higher education was associated with higher perceived understanding (*Coherence*) of MCI ($r = -.53$, $p = .002$). Lower MMSE scores were significantly related stronger beliefs in treatment control ($r = -.39$, $p = .036$). Higher depression scores were significantly related to endorsement of more MCI symptoms ($r = .44$, $p = .015$). We also examined whether beliefs about MCI differed by gender, marital status, living arrangements, and family annual income. Men ($n = 24$) had significantly higher scores for personal control than women ($Z = -2.02$, $p = .04$). Participants with higher annual incomes ($n = 18$) and who lived with spouse or partners ($n = 23$) compared to those with lower incomes and living alone had significantly higher scores on chronic timeline ($Z = -3.34$, $p = .001$, and $Z = -2.61$, $p = .008$, respectively).

Cognitive interview

Results of the cognitive interviews with 5 participants suggested that participants clearly understood the instructions and items in IPQ-MCI and answered appropriately. Thus, no changes were made to the protocol for the remainder of the study. For example, one participant who agreed with the item “My MCI will get worse over time” stated in the interview he responded that way because “it was a natural aging process, even medication can't work.” One participant who agreed with the item “MCI makes me feel stigmatized” stated the reason for that response was, “the bottom of medication for me shows as ‘for Alzheimer's Disease,’ anyone who delivered the medication would take me as having Alzheimer's disease, which is the eventual status.” Another participant disagreed with that same item. That person's reason was that “the diagnosis will not change the life.” Another example is a participant who endorsed “my own behavior” as a cause of MCI and gave the reason as, “MCI may be related to my alcoholism.” An example of a participant who did not endorse “my own behavior” as a cause stated, “I never drink or smoke. The illness should be something natural.”

Discussion

To our knowledge, this is the first theory-driven examination of patients’ beliefs about a diagnosis of MCI. Beliefs about MCI included both medically accurate information and attitudes or beliefs that may or may not be valid. Participants accurately endorsed many symptoms of MCI that were related to cognitive function and did not endorse somatic symptoms. Yet, they endorsed some cognitive and other symptoms that are not specific to MCI and may indicate misperceptions about the meaning of the diagnosis. Many frequently endorsed causes may also be accurate; included heredity and abnormal brain changes. However, whether normal aging or stress is a causative factor in MCI is not clear. Notably, participants did not believe that MCI produces severe emotional distress. They did believe that MCI would last for a long time, but also that it is predictable and controllable by personal strategies and medical treatment. There were no consistent beliefs, however, regarding the short- and long-term outcomes associated with MCI or whether participant believed that they had a coherent understanding of their diagnosis of MCI.

Certain domains of representations from our findings are worthy of further discussion. No previous study has explored beliefs about the causes of MCI in subjects diagnosed with MCI. Most patients with MCI believed that aging causes the condition. This finding is consistent with other reports indicating that older adults believe memory loss to be an inevitable part of normal aging (Hurt, Burns, Brown, & Barrowclough, 2010), which is contrary to current scientific opinion (Drachman, 2006). Our study also found that very few persons attributed MCI to lifestyles factors, such as poor diet, or to certain chronic health conditions (e.g., diabetes, cardiovascular disease), all of which have been suggested as risk factors for MCI (Solfrizzi et al., 2008). Overall, there appears to be both a lack of information and misperceptions about the diagnosis of MCI. However, because we asked participant about what caused his/her MCI, we were unable to differentiate whether participants recognized lifestyle and medical conditions as general risk factors, as opposed to risk factors for them personally. Future work should examine this distinction.

Our findings differed somewhat from a previous study (McIlvane et al., 2008) that indicated that people did not believe they were at risk of progression from MCI to Alzheimer's Disease. Participants in this study were generally uncertain whether MCI could progress to dementia, and almost one third believed MCI would progress to dementia. Most participants believed that MCI had a considerable impact on their lives and caused difficulties for their loved ones, but they did not believe that they had lost their independence as a result of MCI. While over half did not report feeling stigmatized, participants were uncertain as to whether MCI affected how others viewed them. These findings suggest that it may be important to discuss patient's perception of the impact of MCI on daily life in order to address patient's fears and/or concerns, but that those diagnosed with MCI may not in general feel embarrassed or hopeless.

Although all of the participants were recruited from memory clinics that educated patients about the diagnosis of MCI, almost half of the participants did not have a clear understanding of their diagnosis. In this study, cognitive deficits, as measured by the MMSE, were generally not related to beliefs, and, in particular, their belief that MCI is understandable. Educational level was related to their perceived understanding of their diagnosis. Further efforts to tailor patient education about MCI to patients' knowledge and cognitive levels may need to be addressed in clinical practice.

Consistent with previous research (McIlvane et al., 2008), the patients diagnosed with MCI in this study reported relatively low levels of emotional distress regarding their diagnosis. One possible explanation is that eligibility for this study required participants to be diagnosed with MCI for at least three months, which may have allowed time for emotional adjustment to the diagnosis to occur. Similar adjustment has been reported in patients with life-threatening events, such as breast cancer (Costanzo et al., 2007). However, a qualitative study (Lingler et al., 2006) provided another possible explanation. Patients may feel a low level of emotional distress with a diagnosis of MCI because it is not a diagnosis of Alzheimer's disease or other dementia, which they may have feared.

Persons with MCI perceived that MCI is a chronic condition. Interestingly, the perception of chronicity was related to believing that one has little personal control over the illness, worse consequences, and greater emotional distress. This is similar to other research using the IPQ-R to study beliefs about Addison disease, diabetes, hypertension, chronic fatigue syndromes, and Alzheimer's disease (Hagger & Orbell, 2003). Patients who believe that a health problem is chronic also tend to use a higher level of health care services, regardless of the nature of the health problem (Frostholm et al., 2005). We did not measure health care utilization in this study, but this suggests that assessing perceptions of chronicity may identify patients who could benefit from education and interventions to build coping strategies and manage emotional distress related to their diagnosis of MCI.

Limitations of the study design should be acknowledged. First, the study included a small clinic-based sample, the majority of whom were White and highly educated. Given that VA patients composed a large part of the sample, most of the participants were male. The results may not be generalizable to the overall MCI population. Second, we did not further categorize participants according to their subtypes of MCI, because of the small number of participants. Third, the IPQ-MCI needs further psychometric validation in a larger, more heterogeneous sample. On the other hand, the results of this study provide evidence that the IPQ-MCI is feasible for use with older adults with MCI. Both the reasonable amount of time spent on completing the questionnaires and the responses to the cognitive interviews suggest that the IPQ-MCI is relatively easy to use. The assistance from care partners in this study was limited to helping with reading items. For studies involving MCI patients without care partners, investigators may wish to consider using an interview format with the interviewer asking and recording answers while providing participants with the set of questionnaires for reference.

The results of this study suggest a number of avenues for future research. First, previous studies have demonstrated that, after controlling for the severity of health problems, illness representations are significant determinants of health related quality of life (Spain, Tubridy, Kilpatrick, Adams, & Holmes, 2007). In general, people with more symptoms, more chronic timeline, who anticipated worse consequences, and who perceived low control tended to engage in more emotional-focused coping and have worse health outcomes. Future studies should examine whether beliefs about MCI are related to health related quality of life or other domains of mental health. Second, previous qualitative studies reported divergent understandings of MCI among health professionals and caregivers (Frank et al., 2006; Moreira et al., 2008). Because these two groups may have a major influence on how patients think about and cope with their MCI, it would be worthwhile to compare their representations of MCI with those of the patient. This may help bridge any potential gap in their beliefs and facilitate communications and shared decision-making among patients, caregivers, and providers in order to provide more patient-centered care. Third, studies clarifying how the general public and people with a family history of cognitive disorders understand MCI are rare (Dale, Hemmerich, Hill, Hougham, & Sachs, 2008). To systematically compare their representations with those of persons with MCI may help researchers develop strategies to facilitate early detection and diagnosis. Finally, research to develop interventions that can address beliefs that act as barriers to optimal coping and health outcomes is needed. Finally, the Common Sense Model provided a useful framework for organizing and describing peoples' 'lay theories' about their illnesses or health threats and for illuminating the differences between lay theories and medical models of illnesses. As such, it provides many questions that need to be addressed in future research and clinical practice. The theoretical propositions of the CSM; that is, whether beliefs driving coping behaviors and influence health outcomes, were not addressed in this study.

Implications for nursing practice may be premature at this point. However, a number of nursing interventions based on the Common Sense Model (Donovan et al., 2007) suggest that eliciting and discussing patients' beliefs can change misconceptions or address gaps in knowledge in ways that improve patients' quality of life. Nurses working in both memory and primary clinics can utilize such an approach to clarify patients and their families' potential confusions or gaps related to the diagnosis, such as the course of MCI, and the potential stigma or uncertainty related to the label, which may directly influence patients' mental well-being. In addition, many of the potential risk factors of MCI, such as smoking, medical factors (e.g., hypertension, diabetes, depression), or diet (e.g., fish consumption), are modifiable factors. Patients' beliefs about such causes of or risk factors for MCI can directly influence patients' health related behaviors in response to a diagnosis of MCI and how they prevent or better manage these risk factors. Thus, to provide patients with a clear picture of the risk factors of MCI may help patients engage in the healthy behaviors to prevent the further cognitive decline.

Acknowledgments

This work was supported by Sigma Theta Tau International, Beta Eta at-Large Chapter.

The authors wish to acknowledge the support from Dr. Cindy Carlsson, Dr. Amy Kind, and Ms. Gail Hunt for recruitment.

References

Alzheimer's Association. 2011 Alzheimer's disease facts and figures. Alzheimer's & Dementia. 2011; 7(2):208–244.

Aretouli E, Brandt J. Everyday functioning in mild cognitive impairment and its relationship with executive cognition. International Journal of Geriatric Psychiatry. 2009; 25(3):224–233. doi: 10.1002/gps.2325. [PubMed: 19650160]

Blay SL, Piza Peluso Ede T. The Public's ability to recognize Alzheimer disease and their beliefs about its causes. Alzheimer Disease and Associated Disorders. 2008; 22(1):79–85. doi: 10.1097/WAD. 0b013e31815ccd47. [PubMed: 18317251]

Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. Journal of Psychosomatic Research. 2006; 60(6):631–637. doi: 10.1016/j.jpsychores.2005.10.020. [PubMed: 16731240]

Costanzo ES, Lutgendorf SK, Mattes ML, Trehan S, Robinson CB, Tewfik F, et al. Adjusting to life after treatment: distress and quality of life following treatment for breast cancer. British Journal of Cancer. 2007; 97(12):1625–1631. doi: 10.1038/sj.bjc.6604091. [PubMed: 18000503]

Dale W, Hemmerich J, Hill EK, Hougham GW, Sachs GA. What correlates with the intention to be tested for mild cognitive impairment (MCI) in healthy older adults? Alzheimer Disease and Associated Disorders. 2008; 22(2):144–152. doi: 10.1097/WAD.0b013e318161103c. [PubMed: 18525286]

Donovan HS, Ward SE, Song MK, Heidrich SM, Gunnarsdottir S, Phillips CM. An update on the representational approach to patient education. Journal of Nursing Scholarship. 2007; 39(3):259–265. doi: 10.1111/j.1547-5069.2007.00178.x. [PubMed: 17760800]

Drachman DA. Aging of the brain, entropy, and Alzheimer disease. Neurology. 2006; 67(8):1340–1352. doi: 10.1212/01.wnl.0000240127.89601.83. [PubMed: 17060558]

Farias ST, Mungas D, Reed BR, Harvey D, DeCarli C. Progression of mild cognitive impairment to dementia in clinic- vs community-based cohorts. Archives of Neurology. 2009; 66(9):1151–1157. doi: 10.1001/archneurol.2009.106. [PubMed: 19752306]

Folstein MF, Folstein SE, McHugh PR. Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research. 1975; 12(3):189–198. doi: 10.1016/0022-3956(75)90026-6. [PubMed: 1202204]

Frank L, Lloyd A, Flynn JA, Kleinman L, Matza LS, Margolis MK, et al. Impact of cognitive impairment on mild dementia patients and mild cognitive impairment patients and their informants. International Psychogeriatrics. 2006; 18(1):151–162. doi: 10.1017/S1041610205002450. [PubMed: 16403246]

Frostholm L, Fink P, Christensen KS, Toft T, Oernboel E, Olesen F, et al. The patients’ illness perceptions and the use of primary health care. Psychosomatic Medicine. 2005; 67(6):997–1005. doi: 10.1097/01.psy.0000189164.85653.bc. [PubMed: 16314606]

Ganguli M. Mild Cognitive Impairment and the 7 Uses of Epidemiology. Alzheimer Disease & Associated Disorders. 2006; 20(2):S52–S57. doi: 10.1097/00002093-200607001-00007. [PubMed: 16917196]

Gauthier S, Reisberg B, Zaudig M, Petersen RC, Ritchie K, Broich K, et al. Mild cognitive impairment. Lancet. 2006; 367(9518):1262–1270. doi: 10.1016/S0140-6736(06)68542-5. [PubMed: 16631882]

Northern California Neurobehavioral Group. Manual for the Neurobehavioral Cognitive Status Examination. Author; Fairfax, CA: 2001.

Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. Psychology & Health. 2003; 18(2):141–184. doi: 10.1080/088704403100081321.

Hauser RM. Survey response in the long run: The Wisconsin Longitudinal Study. Field Methods. 2005; 17(1):3. doi: 10.1177/1525822X04272452.

Hurt CS, Burns A, Brown RG, Barrowclough C. Perceptions of subjective memory complaint in older adults: the Illness Perception Questionnaire - Memory (IPQ-M). International Psychogeriatrics. 2010:1–11. doi: 10.1017/S1041610209991542.

Joosten-Weyn Banningh L, Vernooij-Dassen M, Rikkert MO, Teunisse JP. Mild cognitive impairment: coping with an uncertain label. International Journal of Geriatric Psychiatry. 2008; 23(2):148–154. doi: 10.1002/gps.1855. [PubMed: 17578843]

Larrieu S, Letenneur L, Orgogozo JM, Fabrigoule C, Amieva H, Le Carret N, et al. Incidence and outcome of mild cognitive impairment in a population-based prospective cohort. Neurology. 2002; 59(10):1594–1599. [PubMed: 12451203]

Leventhal H, Brissette I, Leventhal EA. Cameron LD, Leventhal H. The common-sense model of self-regulation of health and illness. The self-regulation of health and illness behaviour. 2003:42.

Leventhal H, Nerenz DR, Steele DJ. Illness representations and coping with health threats. Handbook of psychology and health. 1984; 4:219–252.

Lingler JH, Nightingale MC, Erlen JA, Kane AL, Reynolds CF 3rd, Schulz R, et al. Making sense of mild cognitive impairment: a qualitative exploration of the patient's experience. Gerontologist. 2006; 46(6):791–800. doi: 46/6/791 [pii]. [PubMed: 17169934]

Lu YFY, Haase JE, Farran CJ. Perspectives of persons with mild cognitive impairment: Sense of being able. Alzheimer's Care Today. 2007; 8(1):75.

McIlvane JM, Popa MA, Robinson B, Houseweart K, Haley WE. Perceptions of Illness, coping, and well-being in persons with mild cognitive impairment and their care partners. Alzheimer Disease & Associated Disorders. 2008; 22(3):284–292. doi: 10.1097/WAD.0b013e318169d714. [PubMed: 18580593]

Moreira T, Hughes JC, Kirkwood T, May C, McKeith I, Bond J. What explains variations in the clinical use of mild cognitive impairment (MCI) as a diagnostic category? International Psychogeriatrics. 2008; 20(4):697–709. doi: 10.1017/S1041610208007126. [PubMed: 18377700]

Morris JC, Edland S, Clark C, Galasko D, Koss E, Mohs R, et al. The consortium to establish a registry for Alzheimer's disease (CERAD). IV. Rates of cognitive change in the longitudinal assessment of probable Alzheimer's disease. Neurology. 1993; 43(12):2457–2465. [PubMed: 8255439]

Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D. The revised Illness Perception Questionnaire (IPQ-R). Psychology & Health. 2002; 17(1):1–16. doi: 10.1080/08870440290001494.

Petersen RC. Mild cognitive impairment as a diagnostic entity. Journal of Internal Medicine. 2004; 256(3):183–194. doi: 10.1111/j.1365-2796.2004.01388.x. [PubMed: 15324362]

Purser JL, Fillenbaum GG, Pieper CF, Wallace RB. Mild cognitive impairment and 10-year trajectories of disability in the Iowa Established Populations for Epidemiologic Studies of the Elderly cohort. Journal of the American Geriatrics Society. 2005; 53(11):1966–1972. doi: 10.1111/j.1532-5415.2005.53566.x. [PubMed: 16274380]

Reitan RM. Validity of the Trail Making Test as an indicator of organic brain damage. Perceptual and Motor Skills. 1958; 8:271–276. doi: 10.2466/PMS.8.7.271-276.

Ries ML, Jabbar BM, Schmitz TW, Trivedi MA, Gleason CE, Carlsson CM, Johnson SC. Anosognosia in mild cognitive impairment: Relationship to activation of cortical midline structures involved in self-appraisal. Journal of the International Neuropsychological Society. 2007; 13(3):450–461. doi: 10.1017/S1355617707070488 [doi]. [PubMed: 17445294]

Roberts JS, Connell CM. Illness representations among first-degree relatives of people with Alzheimer disease. Alzheimer Disease and Associated Disorders. 2000; 14(3):129–136. Discussion 127-128. doi: 10.1097/00002093-200007000-00003. [PubMed: 10994653]

Roberts S, Karlawish J, Uhlmann W, Petersen R, Green RC. Mild cognitive impairment in clinical care: A survey of American Academy of Neurology members. Neurology. 2009; 75(5):425–431. doi: 10.1212/WNL.0b013e3181eb5872. [PubMed: 20679636]

Scarmeas N, Stern Y, Mayeux R, Manly JJ, Schupf N, Luchsinger JA. Mediterranean diet and mild cognitive impairment. Archives of Neurology. 2009; 66(2):216–225. doi: 10.1001/archneurol.2008.536. [PubMed: 19204158]

Shacham S. A shortened version of the Profile of Mood States. Journal of Personality Assessment. 1983; 47(3):305–306. doi: 10.1207/s15327752jpa4703_14. [PubMed: 6886962]

Sheikh JI, Yesavage JA. Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. Clinical Gerontologist. 1986; 5(1-2):165–173. doi: 10.1300/J018v05n01_09.

Solfrizzi V, Capurso C, D'Introno A, Colacicco AM, Santamato A, Ranieri M, et al. Lifestyle-related factors in predementia and dementia syndromes. Expert Review of Neurotherapeutics. 2008; 8(1): 133–158. doi: 10.1586/14737175.8.1.133. [PubMed: 18088206]

Spain LA, Tubridy N, Kilpatrick TJ, Adams SJ, Holmes AC. Illness perception and health-related quality of life in multiple sclerosis. Acta Neurologica Scandinavica. 2007; 116(5):293–299. doi: 10.1111/j.1600-0404.2007.00895.x. [PubMed: 17850407]

Spreen, O.; Strauss, E. A compendium of neuropsychological tests. Oxford University Press New York; 1998.

Suhr JA, Kinkela JH. Perceived threat of Alzheimer disease (AD): the role of personal experience with AD. Alzheimer Disease and Associated Disorders. 2007; 21(3):225–231. doi: 10.1097/WAD.0b013e31813e6683. [PubMed: 17804955]

Sunderland T, Hill JL, Mellow AM, Lawlor BA, Gundersheimer J, Newhouse PA, et al. Clock drawing in Alzheimer's disease. A novel measure of dementia severity. Journal of the American Geriatrics Society. 1989; 37(8):725–729. [PubMed: 2754157]

Tervo S, Kivipelto M, Hanninen T, Vanhanen M, Hallikainen M, Mannermaa A, et al. Incidence and risk factors for mild cognitive impairment: a population-based three-year follow-up study of cognitively healthy elderly subjects. Dementia and Geriatric Cognitive Disorders. 2004; 17(3): 196–203. doi: 10.1159/000076356. [PubMed: 14739544]

Wadley VG, Okonkwo O, Crowe M, Ross-Meadows LA. Mild cognitive impairment and everyday function: evidence of reduced speed in performing instrumental activities of daily living. The American Journal of Geriatric Psychiatry. 2008; 16(5):416–424. doi: 10.1097/JGP.0b013e31816b7303. [PubMed: 18448852]

Werner P. Factors influencing intentions to seek a cognitive status examination: a study based on the Health Belief Model. International Journal of Geriatric Psychiatry. 2003; 18(9):787–794. doi: 10.1002/gps.921. [PubMed: 12949846]

Willis, GB. Cognitive interviewing: a tool for improving questionnaire design. Sage Publications, inc.; 2005.

Wright AM, Holliday RE. Interviewing cognitively impaired older adults: how useful is a cognitive interview? Memory. 2007; 15(1):17–33. doi: 10.1080/09658210601047351. [PubMed: 17479922]

Table 1

Demographic and health information (N = 30)

	Mean (SD)	Range	Frequency (%)
Age in years	76.97 (7.21)	60 – 87	
Education in years	15.25 (3.23)	9.5 – 22	
Male			24 (80%)
White			29 (96.7%)
Retired			30 (100%)
Married			21 (70%)
Living situation: living with a spouse/partner			23 (76.7%)
Family annual income			
< $10,000			0
$ $10,000 - $50,000			18 (60%)
$50,000 - $99,999			8 (26.7%)
$100,000 - $199,999			4 (13.3%)
≥ $200,000			0
Number of chronic illnesses	5 (2.87)	0 –12	
MMSE	27.63 (1.94)	23 – 30	
GDS	1.57 (1.41)	0 – 5	
Months since diagnosis of MCI	24.53 (27.74)	3 – 106	

Table 2

Frequency and Percent of Participants Endorsing Symptoms as MCI-related

Symptom	**Frequency (%)**
Memory loss	28 (93.3)
Forget appointments (need use a calendar)	21 (70%)
Trouble finding words	20 (66.7)
Forget events and/or conversations	18 (60%)
Forget names of friends and/or family members	18 (60%)
Misplace items	17 (56.7)
Repeated questions/statements	15 (50%)
Forget tasks	15 (50%)
Trouble expressing self verbally	15 (50%)
Trouble concentrating or paying attention	12 (40%)
Trouble managing money (e.g. paying bills, making change)	10 (33.3%)
Fatigue	10 (33.3%)
Getting lost in familiar places	9 (30%)
Sleep difficulties	8 (26.7%)
Broken/nonsensical speech	7 (23.3%)
Wandering	7 (23.3%)
Falling	6 (20%)
Loss of strength	5 (16.7%)
Pain	3 (10%)
Breathlessness	3 (10%)
Weight loss	3 (10%)
Stiff joints	3 (10%)
Vision difficulties	3 (10%)
Dizziness	3 (10%)
Hearing loss	2 (6.7%)
Headaches	2 (6.7%)

Table 3

Number and Percent of Participants Endorsing a Cause of MCI

Causes	**Frequency (%)**
Aging	22 (73.3%)
Hereditary, genetic risk factor	16 (53.3%)
Abnormal changes in the brain	15 (50%)
Stress or worry	12 (40%)
Accident or injury	6 (20%)
My own behavior	6 (20%)
Diet or eating habits	5 (16.7%)
My mental attitude (e.g. thinking about life negatively)	5 (16.7%)
My personality	5 (16.7%)
Retirement (e.g. not as active as before)	5 (16.7%)
Chance or bad luck	4 (13.3%)
Family problems or worries caused the MCI	4 (13.3%)
My emotional state (e.g. feeling down, lonely, anxious, empty)	4 (13.3%)
Alcohol	4 (13.3%)
Smoking	3 (10%)
Chronic illness (e.g. Diabetes, High blood pressure)	3 (10%)
Medication side-effects	2 (6.7%)
Obesity	2 (6.7%)
Lack of antioxidants, such as Vitamin C	2 (6.7%)
Pollution in the environment	1 (3.3%)
Overwork	1 (3.3%)
History of stroke	1 (3.3%)
A germ or virus	0 (0)
Poor medical care in my past	0 (0)
Poor immune system	0 (0)

Table 4

Number and Percent of Participants Who Agree, Disagree, or Neither Agree nor Disagree with Items on the Consequences and Coherence Subscale of IPQ-MCI

	Agree or strongly agree	Neither agree nor disagree	Disagree or strongly disagree
Consequences			
MCI is a serious condition	20 (66.7%)	4 (13.3%)	6 (10%)
MCI has major consequences for my life	19 (63.3%)	5 (16.7%)	6 (10%)
MCI causes difficulties for those who are close to me	18 (60%)	4 (13.3%)	8 (26.7%)
MCI does not have much effect on my life	8 (26.7%)	3 (10%)	19 (63.3%)
MCI makes me feel stigmatized	10 (33.3%)	4 (13.3%)	16 (53.3%)
MCI makes me lose my independence	8 (26.7%)	7 (23.3%)	15 (50%)
MCI strongly affects the way others see or treat me	8 (26.7%)	16 (53.3%)	6 (20%)
MCI will progress to dementia	11 (36.7%)	15 (50%)	4 (13.3%)
MCI has serious financial consequences	5 (16.7%)	12 (40%)	13 (43.3%)
MCI makes me lose self-confidence	12 (40%)	9 (30%)	9 (30%)
Coherence			
MCI doesn't make any sense to me	7 (23.3%)	5 (16.7%)	18 (60%)
The symptoms of my condition are puzzling to me	14 (46.7%)	3 (10%)	13 (43.3%)
MCI is a mystery to me	13 (43.3%)	5 (16.7%)	12 (40%)
I don't understand MCI	11 (36.7%)	5 (16.7%)	14 (46.7%)
I have a clear picture or understanding of my condition	11 (36.7%)	6 (20%)	13 (43.3%)

Table 5

Correlations among Representations, Demographic Information and Health History

	1	2	3	4	5	6	7	8
1 Identity	-	-	-	-	-	-	-	-
2 Consequences	.13	-	-	-	-	-	-	-
3 Chronic timeline	.06	.44*	-	-	-	-	-	-
4 Cyclical timeline	-.05	.02	-.11	-	-	-	-	-
5 Personal control	-.05	-.26	-.44*	.14	-	-	-	-
6 Treatment control	-.15	.04	-.31	-.19	.75***	-	-	-
7 Coherence	.23	.06	.03	.17	.01	-.14	-	-
8 Emotional distress	.06	.40*	.51**	-.13	-.30	-.20	-.01	-
9 Age	.19	-.15	-.21	.22	.26	.03	.21	-.36
10 Education	.11	.30	.26	-.36	-.26	-.01	-.53*	.26
11 MMSE	.01	-.29	-.07	.17	-.16	-.39*	.08	-.04
12 GDS	.44*	.23	.19	-.30	-.26	-.03	-.01	.26
13 Months since diagnosis	-.29	-.30	.07	-.10	-.07	.02	-.32	.18
14 Number of chronic illnesses	.28	-.04	-.09	.17	-.29	-.31	.10	-.08

Note:

* $p < .05$

** $p < .01$

*** $p < .001$