Illness Representations in Older Adults with Mild Cognitive Impairment

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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 people diagnosed with the condition and examine correlates (demographic and health) of those beliefs. Thirty individuals 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. People 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.

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 adults 65 and older (Ganguli, 2006; Larrieu et al., 2002). Individuals with MCI may eventually develop Alzheimer's disease (AD) or other dementias, but many do not (Gauthier et al., 2006; Petersen, 2004). With the aging of the population, approximately 11 to 16 million Americans will have AD by 2050, which suggests the number of people with MCI will also be increasing (Alzheimer's Association, 2011).

Most people diagnosed with MCI live in the community. Recent evidence suggests that those 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, 2010; Wadley, Okonkwo, Crowe, & Ross-Meadows, 2008). Even subtle declines in daily 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). People diagnosed with MCI face uncertainty, particularly related to illness progression. A review of 41 cohort studies suggests that, over 3 to 10 years, an average of 32% of people with MCI progress to dementia, whereas the rest either remain stable with MCI or revert to normal cognition (Mitchell & Shiri-Feshki, 2009 **[Query #1: Please reference this citation.]**).

In contrast to AD, there is little public recognition or understanding of MCI nor much available public information that would inform beliefs about MCI (Blay, Peluso, & de Toledo, 2008; Roberts & Connell, 2000; Suhr & Kinkela, 2007; Werner, 2003), even though MCI diagnosis is becoming more prevalent (Roberts, Karlawish, Uhlmann, Petersen, & Green, 2010). It is important to understand what people with MCI believe about the disease 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, affect health outcomes (Leventhal et al., 1984). Five dimensions of representations have consistently been found in empirical research: identity, cause, timeline, 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, 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 et al. (2002) added two new domains: coherence and emotional representations. *Coherence* is one's belief that the

health problem is understandable or makes sense, and *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. However, these relationships 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 a descriptive study with 46 participants (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, stigma). However, those studies differed in findings related to emotional distress as a result of MCI and perceptions of whether MCI could be controlled or slowed. In McIlvane et al.'s (2008) descriptive study (mean age = 77.3), 40% of the sample reported that their likelihood of conversion to AD was zero, and 76% of the sample reported that the disease process was controllable through practical strategies (e.g., staying optimistic, engaging in 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. The researchers 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 (i.e., identity, cause, timeline, consequences, cure/control, coherence, emotional distress). The specific aims

were to (a) describe representations of MCI in people with MCI, and (b) examine the relationships between domains of representations and demographic information and health history.

METHOD
Design and Sample

Thirty individuals diagnosed with MCI participated in this cross-sectional descriptive study. They were recruited from memory clinics at a University Hospital and a Veterans Administration (VA) Hospital in the midwestern United States. Inclusion criteria were: (a) age 60 and older, (b) English speaking, (c) diagnosed with MCI for at least 3 months, (d) community dwelling, (e) capacity to provide informed consent and willingness to participate, and (f) 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 the VA 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 standard deviations below the population norms) in one or more cognitive domains, but not meeting criteria for AD or another dementia, and patient- or care partner-reported decline in instrumental activities of daily living (IADLs). 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, Yesavage & Sheikh, 1986). Neuropsychological testing included the Mini-Mental State 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), the Clock Draw test (Sunderland et al., 1989), Trail Making Test A and B (Reitan, 1958), and the 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 or 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 reporting 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 1 month of participants' recruitment into the study.

Procedure

The study was approved by University Institutional Review Board and the VA Hospital Research and Development committee. Clinicians approached all eligible patients and obtained permission for the first author to contact them. Contacts were made by telephone 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 participants' completion of the remainder of the questionnaires to helping with reading the items. Care partners assisted only 2 of the 30 participants (one who was frail and one with vision difficulty) by reading the questionnaire items to them. They did not help the participants respond to the items. Participants spent an average of 25 minutes ($SD = 7$, range = 13 to 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 individuals (24 men and 6 women) provided informed consent to participate in this study. A subsample of 5 participants (the first 5 who agreed) took part in a cognitive interview (described in Measurements, below). 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 alpha coefficients range from 0.67 to 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) and has some good psychometric properties **[Query #2: Is sentence OK as edited?]**. It consists of 9 items, each a single-item measure of a domain of illness representation. 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 participants' representations, which would not be possible with the single-item measures. Second, we wished to assess the feasibility of older adults 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 University Hospital and VA Hospital memory clinics **[Query #3: Is sentence OK as edited?]**. The IPQ-MCI scale included eight 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, 4 MCI-related items were added: "MCI will progress to dementia," "MCI makes me feel stigmatized," "MCI makes me lose self-confidence," and "MCI makes me lose my independence." For Chronic Timeline, 1 item, "My MCI will get worse over time," was added. For Treatment Control, 1 item, "There are practical ways to manage the symptoms of MCI," was added. For the Causes subscale, 4 items were added to include both risk and protective factors for MCI identified in the literature: "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 Consequences, Chronic Timeline, Cyclical Timeline, Personal Control, Treatment Control, and Coherence subscales, participants responded to each item on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*). The mean score 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 **[Query #4: Please reference this citation.]**). 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 of 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 scale of 0 (*not at all*) to 4 (*extremely*). 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 coefficient) of the modified POMS in this sample was 0.93.

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 older adults with cognitive impairment (Wright & Holliday, 2007). The recommended sample size for cognitive interviews is between 5 and 15 (Willis, 2004). The goal

for this small study was to interview 5 participants. For this study, 7 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 audiorecorded and transcribed verbatim. Investigators compared the participant's ratings with his or her explanations for the given response. If the explanations were consistent with the ratings across all 7 items, we considered the participant's answers to be valid.

Demographic and Health History Information. Demographic information included age (in years), sex, race/ethnicity (five categories), education (in years), retirement status (retired versus still employed), marital status (married versus not married), living arrangement (alone versus with others), and family annual income (<$10,000, $10,000 to $50,000, $50,000 to $99,999, $100,000 to $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 health care 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 MMSE (Folstein et al., 1975); level of depression, measured by the 15-item GDS (Yesavage & Sheikh, 1986); and months since MCI diagnosis.

Data Analysis

SPSS version 16.0 was used for 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 sex, marital status (married versus not married), living arrangement (alone versus with others), and family annual income (<$50,000 versus $50,000+).

RESULTS
Characteristics of the Sample

The average age of participants was 76.97 (*SD* = 7.21 years). Participants were somewhat highly educated, and 29 of 30 were White, which reflected the local population (**Table 1**). The mean GDS score was 1.57 (*SD* = 1.41), which reflects a low level of depressive symptoms. Participants re-

TABLE 1

Demographic and Health Information (*N* = 30)

	Mean (*SD*), Range
Age (years)	76.97 (7.21), 60 to 87
Education (years)	15.25 (3.23), 9.5 to 22
Number of chronic illnesses	5 (2.87), 0 to 12
MMSE score	27.63 (1.94), 23 to 30
GDS score	1.57 (1.41), 0 to 5
Time since diagnosis of MCI (months)	24.53 (27.74), 3 to 106
	n (%)
Men	24 (80)
White	29 (96.7)
Retired	30 (100)
Married	21 (70)
Lives with spouse or partner	23 (76.7)
Family annual income	
<$10,000	0 (0)
$10,000 to $50,000	18 (60)
$50,000 to $99,999	8 (26.7)
$100,000 to $199,999	4 (13.3)
$200,000+	0 (0)

Note. MMSE = Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975), in which scores range from ? to ?, with higher scores indicating ?; GDS = Geriatric Depression Scale (Yesavage & Sheikh, 1986), in which scores range from ? to ?, with higher/lower scores indicating ?; MCI = mild cognitive impairment.

[Query #5: Please provide the missing information in the footnote.]

ported an average of five chronic illnesses (range = 0 to 12); the most frequently reported were high blood pressure (63%), high cholesterol (60%), and arthritis (43%). Seventeen participants (56.7%) had been diagnosed with MCI for less than 1 year, 10 (33.3%) between 1 and 5 years, and 3 (10%) for more than 5 years (**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 provided in **Table 2**. Participants endorsed an average of nine symptoms

TABLE 2 Participants' Endorsement of Symptoms as Related to Mild Cognitive Impairment (*N* = 30)	
Symptom	***n* (%)**
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)
Forget tasks	15 (50)
Repeated questions/statements	15 (50)
Trouble expressing self verbally	15 (50)
Trouble concentrating or paying attention	12 (40)
Fatigue	10 (33.3)
Trouble managing money (e.g., paying bills, making change)	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)
Breathlessness	3 (10)
Dizziness	3 (10)
Pain	3 (10)
Stiff joints	3 (10)
Vision difficulties	3 (10)
Weight loss	3 (10)
Headaches	2 (6.7)
Hearing loss	2 (6.7)

TABLE 3 Participants' Endorsement of Possible Causes of Mild Cognitive Impairment (*N* = 30)	
Cause	***n* (%)**
Aging	22 (73.3)
Hereditary, genetic risk factor	16 (53.3)
Abnormal brain changes	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)
Alcohol	4 (13.3)
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)
Chronic illness (e.g., diabetes, high blood pressure)	3 (10)
Smoking	3 (10)
Lack of antioxidants, such as vitamin C	2 (6.7)
Medication side effects	2 (6.7)
Obesity	2 (6.7)
History of stroke	1 (3.3)
Overwork	1 (3.3)
Pollution in the environment	1 (3.3)
Germ or virus	0 (0)
Poor immune system	0 (0)
Poor medical care in my past	0 (0)

(*SD* = 6.56) they believed were related to MCI. The most frequently endorsed symptoms (by 50% of participants or more) were cognition related, including memory loss (e.g., forgetting appointments) and language (e.g., trouble finding words). The least frequently endorsed symptoms (10% or less) were somatic symptoms common in older age, for example, stiff joints and hearing loss (**Table 2**).

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

Table 4 reports responses to the Consequences and Coherence subscales. For the Consequences subscale, item-total correlations ranged from 0.29 to 0.67, with 9 of the 10 items greater than 0.30. Item-total correlations of the four new items ranged from 0.31 to 0.60. The reliability (Cronbach's alpha coefficient) was 0.84. For the Coherence subscale (5 items), item-total correlations ranged from 0.45 to

TABLE 4

**Participants' Responses to the Consequences and
Coherence Subscales of the IPQ-MCI (*N* = 30)**

Subscale/Item	Agree or Strongly Agree	Neither Agree nor Disagree	Disagree or Strongly Disagree
	n (%)	*n* (%)	*n* (%)
CONSEQUENCES			
MCI is a serious condition	20 (66.7)	4 (13.3)	6 (20)
MCI has major consequences for my life	19 (63.3)	5 (16.7)	6 (20)
MCI causes difficulties for those who are close to me	18 (60)	4 (13.3)	8 (26.7)
MCI makes me lose self-confidence	12 (40)	9 (30)	9 (30)
MCI will progress to dementia	11 (36.7)	15 (50)	4 (13.3)
MCI makes me feel stigmatized	10 (33.3)	4 (13.3)	16 (53.3)
MCI does not have much effect on my life	8 (26.7)	3 (10)	19 (63.3)
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 has serious financial consequences	5 (16.7)	12 (40)	13 (43.3)
COHERENCE			
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)
MCI doesn't make any sense to me	7 (23.3)	5 (16.7)	18 (60)

Note. IPQ-MCI = Illness Perception Questionnaire-Mild Cognitive Impairment.

0.80. There were no new items. The Cronbach's alpha coefficient was 0.84.

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: *agree or strongly agree, neither agree nor disagree, and disagree or strongly disagree.* For Consequences, more than half of the participants agreed that "MCI is a serious condition," "MCI has major consequences for my life," and "MCI causes difficulties for those who are close to me." Consistent with these responses, more than half disagreed with the statement, "MCI does not have much effect on my life." On the other hand, approximately half of the participants disagreed with the statements, "MCI makes me feel stigmatized" and "MCI makes me lose my independence." Half 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 scale scores were normally distributed. For Chronic Timeline (7 items), item-total correlations ranged from 0.09 to 0.75. Six of 7 items were greater than 0.30, including the one new item (0.59). Reliability (Cronbach's alpha coefficient) was 0.69. For Cyclic Timeline (4 items), item-total correlations ranged from 0.29 to 0.61. Three of 4 items were greater than 0.30, and there were no new items. The Cronbach's alpha coefficient was 0.62. For Personal Control (5 items), item-total correlations ranged from 0.24 to 0.74. Four of 5 items were greater than 0.30; there were no new items. Reliability (Cronbach's alpha coefficient) was 0.80. For Treatment

TABLE 5

Correlations Among Illness Representations, Demographic Information, and Health History

	Identity	Consequences	Chronic Timeline	Cyclical Timeline	Personal Control	Treatment Control	Coherence	Emotional Distress
Identity	—	—	—	—	—	—	—	—
Consequences	0.13	—	—	—	—	—	—	—
Chronic timeline	0.06	0.44*	—	—	—	—	—	—
Cyclical timeline	−0.05	0.02	−0.11	—	—	—	—	—
Personal control	−0.05	−0.26	−0.44*	0.14	—	—	—	—
Treatment control	−0.15	0.04	−0.31	−0.19	0.75***	—	—	—
Coherence	0.23	0.06	0.03	0.17	0.01	−0.14	—	—
Emotional distress	0.06	0.40*	0.51**	−0.13	−0.30	−0.20	−0.01	—
Age	0.19	−0.15	−0.21	0.22	0.26	0.03	0.21	−0.36
Education	0.11	0.30	0.26	−0.36	−0.26	−0.01	−0.53*	0.26
MMSE	0.01	−0.29	−0.07	0.17	−0.16	−0.39*	0.08	−0.04
GDS	0.44*	0.23	0.19	−0.30	−0.26	−0.03	−0.01	0.26
Time since diagnosis (months)	−0.29	−0.30	0.07	−0.10	−0.07	0.02	−0.32	0.18
Number of chronic illnesses	0.28	−0.04	−0.09	0.17	−0.29	−0.31	0.10	−0.08

Note. MMSE = Mini-Mental State Examination; GDS = Geriatric Depression Scale.
* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Control (6 items), item-total correlations ranged from 0.35 to 0.74. There was one new item (0.35). The Cronbach's alpha coefficient was 0.81.

Mean scores indicated that participants perceived that MCI will be long lasting (Chronic Timeline: mean = 3.51, SD = 0.63), but somewhat predictable (Cyclical Timeline: mean = 2.74, SD = 0.64) and controllable through personal strategies (Personal Control: mean = 3.31, SD = 0.62) and medical treatment (Treatment Control: mean = 3.44, SD = 0.54). They also reported a low level of emotional distress on the modified POMS scale (mean = 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 coefficients **[Query #6: Is "coefficients" correct?]** ranging from 0.01 to 0.20 (**Table 5**). Significant correlations included more negative consequences of MCI were significantly related to a more chronic timeline (r = 0.44, p = 0.016) and more emotional distress (r = 0.40, p = 0.027). A more chronic timeline was related to less personal control (r = −0.44, p = 0.016) and more emotional distress (r = 0.51, p = 0.004). Personal control was strongly correlated with treatment control (r = 0.75, p < 0.001).

A few demographic and health history variables were significantly related to representations. Higher education was associated with higher perceived understanding (Coherence) of MCI (r = −0.53, p = 0.002). Lower MMSE scores were significantly related to stronger beliefs in treatment control (r = −0.39, p = 0.036). Higher depression scores were significantly related to endorsement of more MCI symptoms (r = 0.44, p = 0.015).

We also examined whether beliefs about MCI differed by sex, marital status, living arrangement, and family annual income. Men (n = 24) had significantly higher scores for personal control than women (Z = −2.02, p = 0.04). Compared with those with lower incomes and who lived alone, participants with higher annual incomes (n = 18) and who lived with a spouse or partner (n = 23) had significantly higher scores on the Chronic Timeline subscale (Z = −3.34, p = 0.001 and Z = −2.61, p = 0.008, respectively). **[Query #7: Is sentence OK as edited?]**

Cognitive Interview

Results of the cognitive interviews with 5 participants suggested that participants clearly understood the instructions and items in the 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 that "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, including 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 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 participants believed 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 patients diagnosed with MCI. Most patients with MCI believed 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 individuals attributed MCI to lifestyles factors, such as poor diet, or to certain chronic health conditions (e.g., diabetes, high blood pressure), 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 participants about what caused their 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 AD. 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 MCI had a considerable effect on their lives and caused difficulties for their loved ones, but they did not believe they had lost their independence as a result of MCI. While more than 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 patients' perceptions of the impact of MCI on daily life in order to address their fears or concerns, but that those diagnosed with MCI may not feel embarrassed or hopeless in general.

Although all of the participants were recruited from memory clinics that educated patients about the diagnosis of MCI, almost half 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 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 3 months, which may have allowed time for emotional adjustment to the diagnosis. Similar adjustment has been reported in patients with life-threatening

illnesses, 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 AD or other dementia, which they may have feared.

People with MCI perceived it as a chronic condition. Interestingly, the perception of chronicity was related to believing 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 syndrome, and AD (Hagger & Orbell, 2003). Patients who believe 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

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 comprised a large part of the sample, most of the participants were men. The results may not be generalizable to the overall MCI population. Second, because of the small sample, we did not further categorize participants according to their subtypes of MCI. 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 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.

RECOMMENDATIONS FOR FUTURE RESEARCH

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 emotion-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). Systematically comparing their representations with those of people with MCI may help researchers develop strategies to facilitate early detection and diagnosis. Research to develop interventions that can address beliefs that act as barriers to optimal coping and health outcomes is also needed.

Finally, the CSM provided a useful framework for organizing and describing individuals' "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 drive coping behaviors and influence health outcomes—were not addressed in this study.

CONCLUSION AND IMPLICATIONS

Implications for nursing practice may be premature at this point. However, a number of nursing interventions based on the CSM (Donovan et al., 2007) suggest that eliciting and discussing patients' beliefs can change misconceptions or address gaps in knowledge in ways that improve quality of life. Nurses working in both memory and primary care clinics can use such an approach to clarify potential confusion or gaps related to the diagnosis, such as the course of MCI and stigma or uncertainty related to the diagnosis, which may directly influence patients' men-

tal well-being. In addition, many of the potential risk factors for MCI, such as smoking, medical conditions (e.g., hypertension, diabetes, depression), and diet (e.g., fish consumption), **[Query #8: Please clarify: Eating fish is a risk factor for MCI?]** are modifiable. Patients' beliefs about such causes of or risk factors for MCI can directly influence patients' health-related behaviors in response to the diagnosis and how they prevent or better manage these risk factors. Thus, providing patients with a clear picture of the risk factors of MCI may help them engage in healthy behaviors to prevent further cognitive decline.

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