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## Journal of Psychosomatic Research



## Role of older adult's illness schemata in coping with Mild Cognitive Impairment

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## ARTICLE INFO

## Article history:

Received 25 September 2011

Received in revised form 14 December 2011

Accepted 9 January 2012

## Keywords:

Illness schemata

Mild Cognitive Impairment

Coping

Aging

Self-care

## ABSTRACT

**Objective:** 1) To describe the illness representations of older persons with Mild Cognitive Impairment (MCI); 2) to describe how older adults cope with MCI; 3) to examine the relationships between illness representations and coping.

**Methods:** Sixty-three older adults with MCI completed questionnaires on demographic and health information, beliefs about MCI (Illness Perception Questionnaire-MCI), and coping with MCI (brief COPE and Self-care Behaviors Checklist).

**Results:** Participants endorsed an average of 7 symptoms that they experienced and believed were related to MCI and an average of 7 potential causes of MCI. Participants tended to believe MCI was chronic, not cyclic, and controllable, but they differed in their beliefs about the consequences, understandability and emotional impact of MCI. Participants used many dementia prevention behaviors and memory aids, some problem-focused and emotion-focused coping strategies, and few dysfunctional coping strategies. Cluster analysis identified three clusters of beliefs about MCI: “few symptoms and positive beliefs,” “moderate symptoms and positive beliefs,” and “many symptoms and negative beliefs.” Those in the “many symptoms and negative beliefs” cluster had significantly more negative beliefs about the consequences, unpredictability (cyclic timeline), and emotional impact of MCI than those in the other clusters. Participants in the “few symptoms and positive beliefs” cluster used significantly fewer memory aids, problem-focused coping strategies, emotion-focused coping strategies, and dysfunctional coping than those in the other two clusters.

**Conclusion:** As suggested by the Common Sense Model, older adults with MCI have beliefs about their MCI and these beliefs are associated with how older adults cope with MCI.

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## 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 [1]. The prevalence of MCI varies from 2.8% to 26.4% in U.S. nationwide studies of adults over 65 years of age [2,3]. Historically, a diagnosis of MCI has been more meaningful to the research community than to the lay public. The diagnosis does not inform the patient in the same way as a diagnosis of dementia, such as Alzheimer's disease (AD). For example, having a diagnosis of MCI neither predicts whether the person will go on to develop dementia nor what type of dementia may develop. Because the cognitive and functional changes associated with MCI are more subtle than those associated with dementia, older adults may be left wondering what their “memory problems” might mean. Finally, there is less certainty in making an

MCI diagnosis than in making a dementia diagnosis. Indeed, a relatively substantial proportion (31%) of individuals diagnosed with MCI revert to “normal” over 18 to 24 months [4]. Altogether, older adults may understandably be confused after having been diagnosed with MCI.

In spite of this, few studies have explored MCI from the individual's perspective, even though people in an early stage of cognitive decline, including MCI, are able to express their own views and needs [5]. Relatively few descriptive and qualitative studies have examined what people think or believe about MCI [6–11]. In these studies, older adults with MCI were able to accurately identify their cognitive symptoms, described some negative consequences of MCI, had diverse emotional responses to their diagnosis, and felt uncertain about whether there would be any progression to AD. Only two studies have examined behaviors after a diagnosis of MCI [7,8]. In these studies, older adults engaged in self-care behaviors, such as use of supportive services and engaged in strategies to prevent dementia. They also used strategies to reduce stress and cope with memory loss. It is important to learn how older adults cope with their cognitive decline since those actions or behaviors may influence their emotional, cognitive, and functional health as indicated by some preliminary results [12,13].

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One way to conceptualize how people understand and manage a health problem is through Leventhal's Common Sense Model (CSM), which proposed that people have beliefs about their health problems. These beliefs are an organized set of cognitive representations (schemas) that can influence how they behave in response to their beliefs [14]. Five domains have consistently been found to be core components of illness representations: the symptoms of the health problem (Identity), beliefs about the origin of the health problem (Cause), temporal ideas (Timeline), ideas about the short- and long-term outcomes of the problem (Consequences), and beliefs about the extent to which one can control or cure the health problem (Control). Moss-Morris [15] later added two new domains: how well people believe they understand their health problem (Coherence) and their emotional response to the problem (Emotional representations). When an individual's beliefs are based on misconceptions, gaps in knowledge, or confusion, the beliefs can be barriers to optimal coping [16]. A meta-analysis of research based on the CSM investigating 23 chronic illnesses [17] summarized that, in general, people with more positive representations of the illness (e.g., more controllability) tended to engage in more positive and active coping strategies, while more negative representations (e.g., more symptoms, more chronic timeline, worse consequences) were related to more emotion-focused coping. However, for some illnesses, different relationships were found. For example, in another meta-analysis of eight studies of patients with acute myocardial infarction, negative representations were related to a higher attendance rate at cardiac rehabilitation [18]. The type of coping or self-care behaviors may differ according to the content of representations. These relationships have not been examined in persons with MCI.

There were three specific aims of this study: 1) To describe the illness representations of older persons with Mild Cognitive Impairment (MCI); 2) to describe how older adults cope with MCI; and 3) to examine the relationships between illness representations and coping.

## Methods

### Participants

Sixty-three participants with MCI were recruited from 3 primary care clinics (geriatrics and internal clinics) and 3 memory clinics (including an Alzheimer's Disease Center) in the Midwest. In the primary care clinics, two geriatricians and one family practice physician referred their patients. In the memory clinics, two geriatric psychiatrists and one neuropsychologist referred their patients. Inclusion criteria were: (1) age 60 or older, (2) English-speaking, (3) diagnosed with MCI at least 3 months prior to the study, (4) community-dwelling, and (5) having the capacity to provide informed consent.

The participants could have been diagnosed with any subtype of MCI based on the criteria from the International Psychogeriatric Association Expert Conference on Mild Cognitive Impairment [19]. More information about the diagnostic procedure can be found in the Wisconsin Alzheimer's Institute affiliated clinic network website (<http://www.wai.wisc.edu/clinics/networkoverview.html>). Participants' MCI status was confirmed by their physicians before their participation in the study to avoid any potential case of progression or reverting to normal status.

Human subject approval for this study was obtained from the university's Social Sciences Institutional Review Board. Recruitment was through referrals from clinicians in geriatrics and memory clinics or by invitation letters sent to individuals in the Alzheimer's Disease Center registries. Written informed consent was obtained during an in-person interview with a research nurse. In the interview, the participants were provided with a set of the questionnaires for reference, but all questions were asked orally and answers were recorded by a trained nurse with a background of working with geriatric patients.

Our previous feasibility study [11] indicated older adults with MCI were able to complete the interview independently from their caregivers. Thus, we only recruited and interviewed individuals with MCI in current study.

### Measurements

#### Illness representations of MCI

The Illness Perception Questionnaire–MCI (IPQ-MCI) was used to measure participants' beliefs about MCI [11]. The IPQ-MCI was developed by modifying the Revised Illness Perception Questionnaire (IPQ-R) [15], which is a generic measure of illness beliefs that can be adapted for use with various illnesses and health threats. The IPQ-MCI was validated in a previous study of 30 older adults with MCI (Mean age=77) [11].

Eight subscales from the IPQ-MCI were included in this study: Identity (27 items), Causes (25 items), Consequences (12 items), Chronic timeline (5 items), Cyclic timeline (4 items), Personal control (6 items), Treatment control (5 items), and Coherence (5 items). The Identity and Causes subscales have dichotomous responses (yes or no). The total number of symptoms participants both experienced and believed to be MCI-related (Identity) and the total number of causes believed to be MCI-related (Causes) were calculated. For the other six 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 more negative beliefs: worse consequences, more chronic or cyclic timeline, less control over the illness through personal efforts or medical treatments, and less perceived understanding of MCI. Reliability (Cronbach's alpha) of these six subscales ranged between 0.76 and 0.90 in this study.

To measure emotional representations, we adopted the 6-item "Emotional representations" subscale from IPQ-R and added two items: "I feel relieved that it is MCI, not Alzheimer's disease," and "My MCI makes me feel uncertain about the future." These two items were added because they were reported by and seemed unique to patients with MCI in previous qualitative studies [6–10]. Participants responded to each item on a 1 (strongly disagree) to 5 (strongly agree) scale. The mean of the subscale was computed with higher scores indicating more emotional distress. The internal consistency (Cronbach's alpha) was 0.82, and item-total correlations ranged between 0.30 and 0.80 in this study.

#### Coping with MCI

Coping with MCI was assessed with measures of general coping strategies and self-care behaviors. General coping strategies were measured by the Brief COPE [20]. The Brief COPE consists of 28 items belonging to 14 sub-domains. Among them, 3 sub-domains (active coping, planning, and instrumental support) belong to the subscale of problem-focused coping, 5 sub-domains (acceptance, use of emotional support, positive reframing, religion, and humor) belong to the subscale of emotion-focused coping, and 6 sub-domains (self-distraction, venting, self-blaming, behavioral disengagement, denial, and substance use) belong to the subscale of dysfunctional coping. Participants responded to each item on a 4-point scale from 0 ("I haven't been doing this at all") to 3 ("I've been doing this a lot"). The mean scores of each subscale and its sub-domains were calculated, with higher scores indicating more use of these behaviors. The scale has been used with older adults with MCI [7]. The Cronbach's  $\alpha$  for the subscales in this study were: 0.88 (problem-focused coping), 0.77 (emotion-focused coping), and 0.73 (dysfunctional coping).

The Self-care Behaviors Checklist consisted of three subscales: dementia prevention behaviors (12 items), use of memory aids (8 items), and use of supportive services (14 items). The subscale of dementia prevention behaviors included use of: mental stimulation, physical exercise, and chronic health condition management. The

items were based on patient education about preventing dementia from the National Institute of Aging (<http://www.nia.nih.gov/Alzheimers/Publications/ADPrevented/>) and Mayo Clinic (<http://www.mayoclinic.com/health/alzheimers-disease/DS01131/DSECTION=prevention>). The memory aids subscale was adopted from the “Mnemonic Usage Subscale” of the “Memory Functioning Questionnaire” [21]. The Memory Functioning Questionnaire has shown high internal consistency (0.83–0.94) and concurrent validity with standardized laboratory memory tests in elderly populations [22], including older adults with MCI [23]. The supportive services subscale included 14 types of services that might be used to cope with cognitive decline, such as financial planning, transportation, and support groups. This checklist was developed by McIlvane et al. and used in their study of 46 older adults with MCI [7]. For items in the Self-care Behaviors Checklist, the responses were dichotomous (“yes” or “no”). The number of “yes” responses was calculated for each subscale. Higher scores indicated more use of each.

To provide evidence of concurrent validity between the checklist of self-care behaviors and general coping strategies, Pearson's correlations were performed. Dementia prevention behaviors were significantly related to memory aids ( $r=0.30, p<.05$ ). Dementia prevention behaviors and memory aids were both significantly related to problem-focused coping ( $r=0.28, p<.05$ ;  $r=0.41, p<.001$ , respectively) and emotion-focused coping ( $r=0.25, p<.05$ ;  $r=0.35, p<.01$ , respectively). There was no relationship between supportive services and general coping strategies. None of the self-care behaviors were related to dysfunctional coping.

#### Demographic and health characteristics

Data on the participants' age, education, family annual income, gender, race/ethnicity, retirement status, marital status, and living arrangements were collected.

Global cognition was measured by the Montreal Cognitive Assessment (MoCA) [24]. A cut-off score of 25 on the MoCA is suggested to identify older adults with possible cognitive impairment [24]. Depression was measured by the 15-item Geriatric Depression Scale (GDS) [25]. Comorbidities were measured with the 20-item Older Americans Resources Service schedule of illnesses [26]. Participants identified whether they had been told by a healthcare provider that they had a health problem, and the interference they perceived from that health problem (0 “no such health problem” to 5 “completely”). Interference from health problems was computed as the mean interference rating for health problems experienced. Family history of cognitive disorders was measured by asking participants whether “any of your biological relationships had any type of cognitive impairment (such as MCI, Alzheimer's disease, vascular dementia),” and “if yes, who the person is.”

#### Data analysis

Analyses were conducted using SPSS 18.0. Descriptive statistics were computed for all study variables. Bivariate correlations between MOCA scores and months since diagnosis and the illness representation and coping variables were computed. Two participants who were recruited from two different primary/geriatric clinics did not complete some sections of MoCA due to vision difficulty (cataract and vision difficulty in general). Their MoCA scores were excluded. A comparison of illness representations and coping variables by recruitment site (primary care versus memory clinics) was computed using independent *t* tests. To describe the beliefs of persons with MCI, a cluster analysis of the eight domains of illness representations except the Cause subscale was performed in two steps as suggested by Clatworthy et al. [27]. According to Clatworthy et al. [27], the minimal number of cases for cluster analysis is 42. First, a Hierarchical Cluster Analysis using Ward's Method identified the number of homogenous clusters. The dendrogram plot was examined to determine

the number of clusters. Second, using the number of clusters identified in step 1, a K-means Cluster Analysis of the eight domains of illness representations was performed.

Whether demographic and health variables differed by cluster was assessed using one-way analyses of variance (ANOVA) for equal variances across groups for continuous variables (i.e., age, education, global cognition, depression, number of illnesses, interference from illnesses, and months since diagnosis of MCI), and Chi-square test for categorical variables (i.e., family annual income, marital status, gender, and recruitment site). Whether illness representations and types of coping differed by cluster was examined using analysis of covariance (ANCOVA) for equal variances across groups, controlling for education, interference from illnesses, depression, and global cognition. When the ANOVA or ANCOVA was significant, LSD post-hoc tests were used to determine which groups differed significantly. Control variables were chosen based on previous research and theory about coping and the CSM. To control for family-wise error, the false discovery rate (FDR) [28] was used by applying the MULTPROC program in SAS. In FDR, the level of *q* is similar to the traditional *p* value, which should be less than 0.05.

## Results

#### Sample characteristics

Table 1 describes the demographic and health characteristics of the study sample. The average age was 81.16. The average level of education was equal to a college degree, and the majority of participants described themselves as White, which reflects the area of the Midwest where recruitment was conducted. The mean level of depressive symptoms was low, but 4 (6.3%) persons screened positive for possible clinical depression as indicated by the cut-off score (GDS>5). There were 82.5% of the participants who scored 25 or less on the MoCA. Participants from memory and primary clinics did not differ in their MoCA scores ( $t=-1.00, p=.324$ ).

#### Illness representations

Table 2 shows the descriptive data for the illness representations for the total sample. Overall, participants reported an average of 7 symptoms (Identity) that they experienced and believed to be MCI-related. The symptoms endorsed by over half of participants were all cognitive symptoms (i.e., memory loss, misplace items, forget events and/or conversations, forget names of friends and/or family members, and trouble finding words). Participants reported an average of 7 causes of MCI ( $SD=5.72$ ). Only three causes (aging, hereditary, and abnormal brain change) were endorsed by over half of the participants. In general, participants agreed with statements included in the Chronic timeline, Personal control, and Treatment control scales, and disagreed with statements included in the Cyclic timeline scale. Participants had diverse responses to statements about Consequences. For example, 76.2% agreed with “MCI is a serious condition,” 58.8% disagreed with “MCI has serious financial consequences,” while equal numbers (42.9%) of participants agreed and disagreed with “MCI strongly affects the way others see or treat me.” Participants also varied in their responses to statements in the Emotional representations scale; for example, 65.1% disagreed “My MCI makes me feel angry,” 82.6% agreed, “I feel relieved that it is MCI, not Alzheimer's disease,” while 46.1% agreed, but 38.1% disagreed, “My MCI makes me feel uncertain about the future.” Finally, only around half of participants believed they had a clear understanding of MCI (Illness coherence scale).

There were no significant correlations between MoCA scores and any domain of illness representations. Months since diagnosis was significantly positively correlated with only illness coherence. Participants who had been diagnosed with MCI longer had more positive perceptions of their understanding of MCI ( $r=-0.32, p=.031$ ). Participants recruited from primary clinics perceived more cyclic timeline than those recruited from memory clinics ( $t=2.86, p=.006$ ).

#### Cluster analysis of illness representations

Three distinct clusters of illness representations were identified. Identity scores dominated the classification of cases. Participants in cluster 1 ( $n=18$ ) reported a small number of MCI-related symptoms, less negative consequences, and less negative emotional responses. This cluster was labeled “few symptoms and positive beliefs”. Participants in cluster 2 ( $n=27$ ) reported some MCI-related symptoms but few negative consequences or emotional responses. This cluster was labeled “moderate symptoms and positive beliefs”. Participants in cluster 3 ( $n=18$ ) reported a high number of MCI-related symptoms and more negative consequences and emotional responses. This cluster was labeled “many symptoms and negative beliefs”.

Table 1 shows the demographic and health characteristics by cluster. There were no significant differences except that a significantly higher percentage of participants in the “moderate symptoms and positive beliefs” cluster (66.7%) had a family history

**Table 1**  
Demographic and health background for the sample and by cluster

	Total (n=63)	"Few symptoms and positive beliefs" cluster (n=18)	"Moderate symptoms and positive beliefs" cluster (n=27)	"Many symptoms and negative beliefs" cluster (n=18)	Cluster difference: ANOVA or $\chi^2$
Age, mean (SD)	81.16 (8.31)	83.61 (9.93)	79.30 (6.92)	81.50 (8.26)	1.50
Education in years, mean (SD)	15.87 (3.42)	16.36 (4.23)	16.22 (3.30)	14.83 (2.57)	1.16
Family annual income <\$50,000, frequency (%)	30 (48.5%)	8 (53.4%)	13 (56.5%)	9 (50%)	0.31
White, frequency (%)	61 (96.8%)	16 (88.9%)	27 (100%)	18 (100%)	5.16
Retired, frequency (%)	61 (96.8%)	18 (100%)	25 (92.6%)	18 (100%)	2.75
Married, frequency (%)	35 (55.6%)	10 (55.6%)	15 (55.6%)	10 (55.6%)	1.40
Male, frequency (%)	30 (47.6%)	6 (33.3%)	13 (48.1%)	11 (61.1%)	2.79
MoCA (0–30), mean (SD) <sup>†</sup>	22.20 (3.34)	22.71 (3.00)	22.65 (2.87)	21.00 (4.14)	1.56
GDS (0–15), mean (SD)	2.30 (2.12)	1.50 (2.09)	2.42 (2.04)	2.94 (2.11)	2.19
Number of illnesses (0–21), mean (SD)	5 (2.54)	4 (1.94)	5 (2.79)	5 (2.75)	0.44
Interference from illnesses (0–5), mean (SD)	1.28 (0.63)	1.22 (0.53)	1.22 (0.62)	1.45 (0.75)	0.81
Family history of cognitive disorders, frequency (%)	30 (47.6%)	6 (33.3%) <sup>a</sup>	18 (66.7%) <sup>b</sup>	6 (33.3%) <sup>a</sup>	6.87*
Months since diagnosis of MCI, mean (SD)	29 (28.13)	19 (16.78)	31 (29.76)	34 (28.02)	1.07
Participants recruited from primary clinics, frequency (%)	25 (39.7%)	8 (44.4%)	7 (25.9%)	10 (55.6%)	4.20

When the F-test was significant, means with different superscripts are significantly different from each other; means with the same superscript are not significantly different (LSD's post hoc test,  $p < .05$ ). <sup>†</sup>(N=61 due to missing data).

\*  $p < .05$ .

of cognitive disorders compared to those in the "few symptoms and positive beliefs" cluster (33.3%) or the "many symptoms and negative beliefs" cluster (33.3%) ( $\chi^2 = 6.87, p = .032$ ).

Table 2 shows the mean scores for each domain of illness representations by cluster and the ANCOVA and LSD post-hoc test results. There were significant differences by cluster for Identity, Consequences, Cyclic Timeline, and Emotional Representations. Post-hoc tests indicated that the "many symptoms and negative beliefs" cluster members believed that there were significantly more negative consequences, a more cyclic timeline of MCI, and perceived more emotional distress from MCI than other two clusters. All 3 clusters were significantly different from each other for Identity.

**Coping**

Descriptive statistics for the coping variables for the total sample are in Table 2. Overall, participants engaged in a high frequency of dementia prevention behaviors. They also used memory aids frequently, but used very few supportive services. The most frequently used supportive services were housekeeping assistance/help (46.0%), financial planning (28.6%), and transportation services (27.0%). They used some problem- or emotion-focused coping strategies, but very few dysfunctional strategies.

Fig. 1 displays the means and 95% confidential intervals (95% CI) for each sub-domain in the brief COPE. "Acceptance" was the most frequently used strategy, while "substance use" was the least frequently endorsed.

**Table 2**  
Descriptive data for illness representations and coping for the sample and by cluster

	Total		Few symptoms and positive beliefs" cluster (n=18)	"Moderate symptoms and positive beliefs" cluster (n=27)	"Many symptoms and negative beliefs" cluster (n=18)	Cluster difference ANCOVA <sup>†</sup>	
	Mean (SD)	Range				F (2, 60)	q value
<b>Illness representations</b>							
Identity	7 (4.25)	0–17	1.67 (1.57) <sup>a</sup>	6.56 (1.34) <sup>b</sup>	12.11 (1.64) <sup>c</sup>	194.68	<.001
Consequences	3.21 (0.69)	1.20–4.80	2.78 (0.66) <sup>a</sup>	3.20 (0.61) <sup>a,b</sup>	3.65 (0.55) <sup>b</sup>	6.45	.007
Chronic timeline	3.82 (0.76)	1.57–5.00	3.67 (0.84)	3.76 (0.76)	4.06 (0.67)	1.31	.391
Cyclic timeline	2.75 (0.72)	1.75–4.25	2.39 (0.52) <sup>a</sup>	2.71 (0.70) <sup>a</sup>	3.15 (0.75) <sup>b</sup>	4.89	.022
Personal control	2.57 (0.65)	1.00–4.40	2.44 (0.74)	2.50 (0.51)	2.79 (0.74)	0.41	.669
Treatment control	2.74 (0.63)	1.00–4.80	2.51 (0.59)	2.81 (0.41)	2.87 (0.85)	0.47	.669
Coherence	2.80 (0.87)	1.00–4.40	2.51 (0.85)	2.74 (0.87)	3.17 (0.80)	1.04	.460
Emotional representations	2.75 (0.66)	1.88–4.50	2.34 (0.39) <sup>a</sup>	2.74 (0.61) <sup>a</sup>	3.18 (0.69) <sup>b</sup>	7.69	.003
<b>Coping</b>							
Dementia prevention behaviors	9.15 (1.83)	5–12	9.22 (1.80)	9.15 (2.19)	9.18 (1.84)	0.72	.574
Use of memory aids	5.76 (1.95)	1–8	4.50 (1.92) <sup>a</sup>	6.46 (1.53) <sup>b</sup>	6.25 (1.84) <sup>b</sup>	7.40	.003
Use of supportive services	2.11 (2.29)	0–9	2.22 (2.39)	1.38 (1.65)	3.19 (2.76)	2.34	.165
Problem-focused coping	1.30 (0.88)	0–3.00	0.85 (0.86) <sup>a</sup>	1.54 (0.94) <sup>b</sup>	1.41 (0.67) <sup>b</sup>	4.59	.025
Emotion-focused coping	1.47 (0.62)	0–2.90	1.04 (0.67) <sup>a</sup>	1.60 (0.59) <sup>b</sup>	1.68 (0.42) <sup>b</sup>	8.30	.003
Dysfunctional coping	0.56 (0.40)	0–1.75	0.30 (0.31) <sup>a</sup>	0.58 (0.38) <sup>b</sup>	0.76 (0.32) <sup>b</sup>	9.00	<.001

Note. When the F-test was significant, means with different superscripts are significantly different from each other; means with the same superscript are not significantly different (LSD's post hoc test,  $p < .05$ ).

<sup>†</sup>ANCOVA controlling for education, interference from illnesses, depression, and global cognition.

Correlational analyses indicated that higher MoCA scores were associated with use of more dementia prevention behaviors ( $r = 0.28, p = .03$ ) and fewer services ( $r = -0.27, p = .043$ ). Months since diagnosis of MCI was significantly related to more problem-focused coping ( $r = 0.32, p = .034$ ), more dysfunctional coping ( $p = .64, p < .001$ ), and more supportive services ( $r = 0.37, p = .014$ ). Participants recruited from primary care clinics used significantly more services than those from memory clinics ( $t = 3.99, p < .001$ ), even though their MoCA scores did not differ.

*Relationships between illness representations and coping*

Table 2 also shows the mean scores for each domain of coping by cluster and the ANCOVA and LSD post-hoc test results. The ANCOVA identified significant cluster differences for Memory aids, Problem-focused coping, Emotion-focused coping, and Dysfunctional coping. Post-hoc tests indicated that participants in "few symptoms and positive beliefs" cluster used fewer memory aids, problem-focused coping strategies, emotion-focused coping strategies, and dysfunctional strategies than the other two clusters.

**Discussion**

This is the first theory-driven study to examine the relationship between illness representations and coping in older adults with

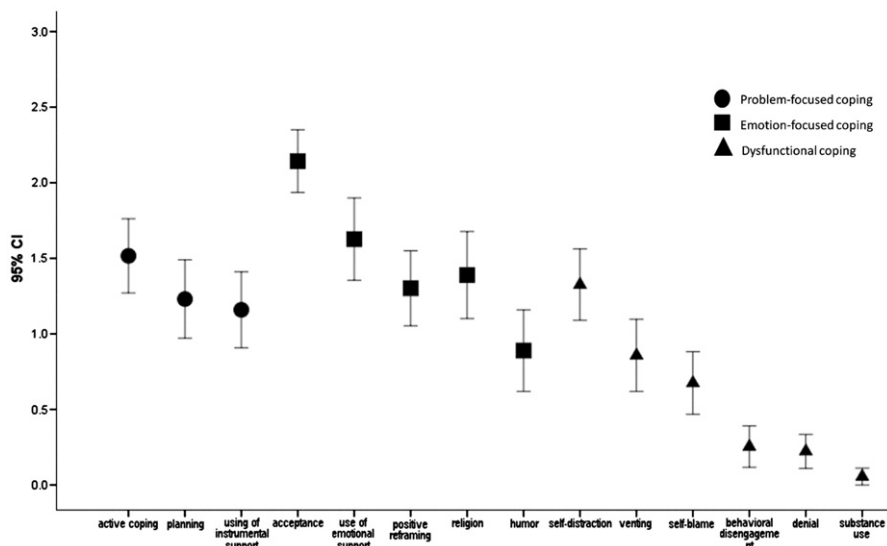


Fig. 1. Sub-domains of problem-focused coping, emotion-focused coping, and dysfunctional coping.

MCI. The CSM provides a theoretical explanation of how lay people's beliefs about their health conditions are related to their coping or self-management behaviors. We found such support for the CSM in older adults with MCI, but the directions of the associations were different from some of the previous studies [17], which may be explained by what is unique about Mild Cognitive Impairment.

The findings of illness representations, except the newly added domain of Emotional representations, are consistent with a previous study of 30 older adults with MCI recruited from memory clinics [11]. There were no consistent beliefs regarding the impact of MCI on participants' lives (consequences), whether they had a coherent understanding of their diagnosis of MCI (coherence), or whether MCI produced emotional distress (emotional representations). These results suggest that there are individual differences in beliefs about MCI and that further research has to better understand the antecedents and consequences of individual differences in beliefs.

Regardless of older adults' cognitive deficits as assessed by MoCA, education, depressive symptoms, and co-morbid health problems, three clusters of beliefs about MCI were identified that reflected differences in beliefs about the symptoms associated with MCI and the consequences, predictability, and emotional impact of MCI. Previous studies of illness schemata in persons with cognitive disorders secondary to brain injury [29] and in hypertension [30] had similar results. In those studies, 3 clusters of illness representations emerged with one cluster representing a large number of symptoms plus negative beliefs while the other two clusters had relatively fewer symptoms and positive beliefs. Taken together, these results suggest that the influence of symptoms on one's overall illness representation is large and may be the major motivation for using coping strategies.

Consistent with previous research on illness representations [17], significant correlations between identity, consequences, and timeline were found, and the correlations were further supported by the differences found among the 3 clusters. However, in contrast to two previous studies [29, 30], in this study controllability did not differ by cluster, and participants in all clusters endorsed strong beliefs that MCI is controllable through personal effort and medical treatment. Strong beliefs about controllability over cognition-related problems are consistent with previous studies of both cognitively normal older adults [31] and older adults with MCI [7].

Overall, participants in our study engaged in many dementia prevention behaviors and used many memory aids, but very few supportive services. They used both emotion- and problem-focused

coping strategies, but very few dysfunctional strategies. The low use of dysfunctional strategies may help explain why there was no relationship between dysfunctional strategies and any of the self-care behavior measures. The low use of supportive services makes sense given that persons with MCI usually maintain relatively intact activities of daily living; thus, they may need only a few services that reflect higher-level activities (e.g., financial planning, legal services).

Compared to participants in the "few symptoms and positive beliefs" cluster, those in the other two clusters used significantly more memory aids, problem-focused coping strategies, and emotion-focused coping strategies. Interestingly, they also used more dysfunctional strategies. One possible explanation is that participants in this cluster, who both had more symptoms and more negative beliefs about MCI, had more to cope with and were using as many coping strategies as they could find, including strategies that may not be helpful. On the other hand, some of the strategies labeled 'dysfunctional' may actually be helpful when a stressor cannot be changed, which may be the case for some of the symptoms experienced by these participants. Support for such an interpretation can be found in the frequency of using different types of strategies in the dysfunctional coping. The most frequently used strategy in this subscale was "self-distraction" while the least frequently used strategies were "behavioral disengagement", "denial", and "substance use."

The findings from this study may be useful in developing interventions to assist older adults in coping with MCI. The Representational Approach to Patient Education, an intervention approach based in part on the CSM, suggests that eliciting and discussing patients' beliefs can change potential barriers (e.g., misconceptions, gaps in knowledge) in ways that help patients better manage their health conditions [32]. This approach has effectively directed interventions to reduce barriers to pain management and coping in cancer patients [33], perception of symptom burden in older breast cancer survivors [34], and communication difficulty in patients and their surrogates in end-of-life care [35]. Future research can test whether such an approach can be efficacious in improving older adults' strategies for coping with their MCI.

In clinical practice, two groups of older adults with MCI, one group endorsing a large number of symptoms as MCI-related and negative beliefs and the other with very few symptoms and positive beliefs, should be addressed equally. Although the group endorsing many symptoms made many efforts to cope with their MCI, they simultaneously possessed many negative and sometimes incorrect beliefs

about MCI. Clinician may focus on identifying and addressing these negative beliefs and corresponding distress from the diagnosis of MCI. The group endorsing few symptoms as MCI-related, in fact, was not different from the high symptom group in their level of global cognition as measured by the MoCA. There are a number of possible explanations. The differences in beliefs and symptoms may be a function of personality or other personal strengths, such as optimism, that influence perception. Or, the specific cognitive deficits may have been different among the clusters and thus have had a differential impact on everyday symptom experience and functioning which can be related to beliefs about MCI. Future research should investigate these possibilities. How physicians communicate the diagnosis of MCI and its implications is another important avenue for future study. In this study, there were only a few significant differences between participants recruited from primary care clinics and those from specialty memory clinics in some domains of their beliefs about MCI (i.e., perceiving more cyclic timeline) and coping (using more supportive services), but this study was not specifically designed to examine this question. There may be other important outcomes that are related to the types of information and support offered by health care providers to patients with MCI that should be ascertained.

The strengths of this study include recruiting participants with MCI based on a formal diagnosis and including a very old age group with an average age of 81. Participants were recruited from both primary care clinics in the community and memory clinics associated with an academic medical center, ADRC, which potentially increases the generalizability of the findings. This study operationalized coping to include the specific behaviors suggested as necessary to manage MCI as well as general coping strategies. In contrast, many of the previous studies only measured very general coping behaviors/strategies [17]. However, the measure of self-care behaviors was a dichotomous checklist, which limits its use in statistical analysis. There may also have been both floor and ceiling effects in this measure. Second, the sample was small, and participants were all recruited from the Midwest of the United States. Thus, these results may not be generalizable to the entire MCI population. Third, given the nature of a cross-sectional study, casual relationships could not be determined. Fourth, more objective measures of health indicators would be useful. Older adults with MCI were able to report their own beliefs about MCI in this study and in a previous study (10). However, some participants' responses may reflect social desirability which may have biased the results. Finally, although all participants' diagnostic status were confirmed by their physicians within one month of this study, we cannot be positive that the diagnostic criteria for MCI [19] were consistently used in the community as compared to the memory clinics (e.g., 1 SD, 1.5 SD, or 2 SD below the normative data in certain cognitive domains). On the other hand, MoCA was used as an assessment of global cognition, and MoCA results were consistent with a diagnosis of MCI. Regardless, participants in this study were informed about the diagnosis of MCI, and the data support the theoretical propositions that individuals form representations about an illness when given a diagnosis.

Overall, the findings indicated that the understanding a person's illness schemata might uncover important clinical implications in terms of an older adult's reactions and adjustment after a diagnosis of MCI. Future research should be based on prospective designs that will allow the examination of the dynamic process of illness representations and coping and their relation to longer term outcomes in older adults with MCI.

### Acknowledgment

This work was supported by Sigma Theta Tau International/Midwest Nursing Research Society Research Grant, Gwen Shapiro Wisconsin Distinguished Fellowship and Eckburg Fund Research Award from University of Wisconsin-Madison.

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