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Self-Initiated Health Behaviors Following a Diagnosis of Mild Cognitive Impairment

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Abstract

The purpose of this study was to characterize the health related activities that patients self-initiate after being diagnosed with Mild Cognitive Impairment (MCI). Fifty-three persons with MCI were queried regarding health related activity changes made as a direct result of the MCI diagnosis, excluding activities which a) they were performing prior to their diagnosis, or b) were formally recommended by a clinician. Qualitative description was used to analyze responses. Most participants (62%) reported initiating one or more health related activities. The activities fell into three distinct categories: behaviors that were symptom driven (e.g., cognitive exercises), health promoting (e.g., dietary changes), or general increases in activity level. Activities reported by this sample encompassed many practices for which there is limited evidence for a potential impact on the clinical course of MCI. However, findings provide insight into the types of interventions that may be most attractive to those living with an MCI diagnosis.

Mild cognitive impairment (MCI) is a syndrome of subtle cognitive decline that occurs among otherwise normally functioning older adults (Petersen, Stevens, Ganguli, Tangalos, Cummings, & DeKosky, 2001). The symptoms exhibited by persons with MCI are not severe enough to warrant a dementia diagnosis although affected individuals progress to Alzheimer's disease (AD) at an increased rate, leading some clinicians and researchers to refer to MCI as a dementia precursor state (Peterson, 2000). Robust, easily accessible predictors of eventual progression from MCI to dementia are lacking (Petersen et al., 2009), and there are no Food and Drug Administration-approved treatments indicated for MCI. Consequently, persons diagnosed with MCI live with prognostic uncertainty and may experience a sense of powerlessness to affect the ultimate outcome of their cognitive trajectory (Lingler et al., 2006). Qualitative research has shown that while some individuals diagnosed with MCI demonstrate a nuanced understanding of the prognostic uncertainty associated with MCI, others either equate the syndrome with AD, or maintain the belief that progression to AD is inevitable (Lingler et al., 2006).

After cancer, AD is the second most feared disease among American adults (Anderson, Day, Beard, Reed, & Wu, 2009). Given that the symptoms of MCI overlap significantly with those of early AD (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005; Petersen et al., 2009), and in some cases, may even represent preclinical AD, it is reasonable to speculate that persons affected by MCI may perceive the syndrome as a potential threat to their health. The Common Sense Model of Illness Perception suggests that upon appraising a perceived health threat, an individual may adopt health behaviors or engage in other adaptive responses to that threat (Leventhal, Nerenz, & Steele, 1984). Support for the application of this model in AD is found in Chao and colleagues (2008) research. This group has documented that asymptomatic individuals at high risk for AD are likely to initiate health behaviors ranging from pharmacotherapies to lifestyle changes within one year of learning of their genetic risk status (Chao et al., 2008). Complementing this work, one of the few studies on patients' beliefs about MCI suggests that affected persons view various

nonpharmacological interventions as protective against progression to AD (McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). However, little is known of the extent to which such interventions are actually implemented within the MCI population. The current report, therefore, fills a significant gap in the literature by describing those MCI health-related activities, broadly defined, that are self-initiated by individuals with MCI following the receipt of this diagnosis. The purpose of this brief report is to articulate the potential range of health-related activities that are initiated and practiced by those diagnosed with MCI.

Methods

With approval from the University of Pittsburgh Institutional Review Board, we conducted a cross-sectional, interview based study to characterize the health-related activities (HRA) adopted by persons recently diagnosed with mild cognitive impairment. This investigation was embedded within a larger study designed to comprehensively examine illness perception among persons with MCI and their family members. Patients with MCI were recruited from the Memory Disorders Clinic and Alzheimer's Outreach Center of the University of Pittsburgh Alzheimer's Disease Research Center (ADRC; P50 AG05133). The rationale for recruitment within an ADRC was that MCI diagnoses are generally conferred in subspecialty or research clinics, as opposed to community practices. While ADRC samples may lack generalizability, recruiting from such a setting ensures both consistency in the application of MCI diagnostic criteria and a standardized approach to the disclosure of diagnostic information to participants (Lingler et al., 2006).

In addition to meeting the basic enrollment criteria for the ADRC (Lopez et al., 2000), all participants held an ADRC consensus diagnosis of MCI, defined as a subjective complaint of cognitive changes and objective evidence of an isolated deficit in a single cognitive domain (e.g., memory); or, mild deficits in multiple domains. All participants were greater than 50 years of age, community-dwelling and provided written consent to participate. Potential participants were identified through the ADRC registry and approached by the ADRC recruitment coordinator about being contacted for the primary study in which this investigation was embedded. A total of 61 patients were approached for the current study, with 53 ultimately providing written informed consent to this research.

Data collection

Basic sociodemographic and clinical characteristics were abstracted from each consenting participant's ADRC record. Clinical characteristics included MCI type (amnesic or other), global cognitive functioning as measured by the Mini Mental State Exam (Folstein, Folstein, & McHugh, 1975) and depressive symptomatology as measured by the Hamilton Depression Rating Scale (Hamilton, 1960). Participants were interviewed at the location of their choice, usually in their homes. Interviews lasting approximately one hour were conducted by a nurse practitioner with expertise in memory disorders or a graduate student in public health who held a certificate in gerontology. Following a battery of questions about MCI-related illness representation and planned adherence to formal recommendations by healthcare providers, participants were asked what, if any, additional changes they have made as a direct result of being diagnosed with MCI. Responses to that open-ended question were recorded verbatim and participants were encouraged to describe as many self-initiated activities as they wished, excluding only those activities which a) they had been performing prior to receiving a diagnosis of MCI, or b) were formally recommended by a health care provider. With participants' consent, systematic reviews of the medical and social work notes from the ADRC diagnostic disclosure session were conducted and clinical recommendations pertaining to the MCI diagnosis were abstracted. This process ensured that those behaviors reported to be self-initiated had not been formally recommended by a

clinician. If a participant described an activity that was determined by chart review to have been recommended by a healthcare provider, the activity was not counted as self-initiated.

Data analysis

We used qualitative description as delineated by Sandelowski (2000) to characterize the self-initiated health-related activities (HRAs) adopted by persons recently diagnosed with mild cognitive impairment. As the first 20 interviews were conducted, the last author of this paper iteratively coded responses to the open-ended question about self-initiated activities in response to the MCI diagnosis. The iterative coding process yielded 7 discrete types of activities. Definitions for each were developed to ensure that categories were mutually exclusive and a set of 7 codes was implemented for the remaining data. Data from 10 cases were coded by 2 coders (the first and last authors) and inter rater reliability was confirmed. Through a process of team meetings and consensus building discussions among the research team (4 members), a thematic analysis was conducted and the activities adopted by subjects were ultimately regrouped to reflect 3 broader, overarching categories.

Results

The sample for current analysis consisted of the initial group (n = 53) of patients with MCI to be recruited into the parent study. Participants included more men (n = 32; 60%) than women; the average age was 71 years (s.d. = 9.09), most were Caucasian (n = 49; 93%), and had educational attainment beyond high school (n = 38; 72%. As shown in Table 1, there were no significant sociodemographic or clinical differences between those who did and did not endorse adopting an MCI-related HRA.

Description of Health-Related Activities

When participants were asked to describe specific HRAs that they had initiated as a direct result of being diagnosed with MCI, the majority of persons in our sample provided at least one example of a newly initiated or intensified HRA. By contrast, 20 participants denied initiating any new health behaviors beyond those which were recommended by their healthcare providers. Most often, those denying the initiation of new health behaviors simply stated “nothing” when asked what HRAs they had self-initiated. To ensure that the participant understood the question, interviewers probed by stating, “For example, since being diagnosed with MCI, have you made changes to your diet or exercise routine, or started taking any vitamins or supplements?” For each HRA that a respondent reported, the interviewer verified that the activity was initiated in direct response to his or her MCI diagnosis. Thirty-three of the 53 participating patients reported initiating one or more HRA with a total of 60 specific activities being described. As outlined in Table 2, these self-initiated activities fell into three general categories: symptom-driven behaviors, health promotion activities, and *increases in general activity*.

Symptom-Driven Behaviors

The category of symptom-driven behaviors encompassed those HRAs that were adopted with the specific intent of minimizing the impact of MCI symptoms and included: *cognition stimulating behaviors*, *compensatory activities*, and *safety or planning activities*. Overall, symptom-driven behaviors were the most commonly reported HRA initiated by persons with MCI. Out of the 60 responses offered by 33 patient participants, 31 responses fell within this overarching category; and most of the participants (n = 27) endorsed at least one symptom-driven behavior. Participants’ descriptions of cognitive stimulation included both focused activities, like using “memory exercise workbooks,” and multipronged approaches. An example of the latter is “using a book with brain games, [doing] crossword puzzles, and reading,” as provided by a 59 year-old participant with 16 years of education. Compensatory

activities to lessen the impact of cognitive impairment on daily life included using cueing and reminder systems, increasing one's level of organization or structure in daily routines, and other simplifying strategies. This category included not only basic changes in routine, but for a few individuals, major life changes. Written reminders such as "using the calendar more," as reported by an 88 year-old woman with 15 years of education, were the most routinely cited adaptations to compensate for cognitive impairment. More substantial changes were noted less often and included such activities as downsizing one's home and reducing one's business responsibilities. Overall, one quarter of all participants provided a response falling into the subcategory of compensatory activities.

Safety precautions and planning behaviors comprised the third subcategory of symptom-driven behaviors. The following statement by a 63 year-old woman with 21 years of education typified the responses falling within the safety and planning subcategory, "[I am] more careful about letting people know my plans and where I am [and] carrying [my] cell phone on me." In addition to planning for one's immediate well-being, participants in this sample engaged in long-term planning activities such as "make a living will and power of attorney papers...get [the] gravesites in order," as stated by a 54 year-old man with 18 years of education. As with compensatory strategies, planning activities also encompassed major life changes for some individuals. The most striking example was provided by a 59 year-old woman with 16 years of education who resigned from her job as a school teacher after learning of her MCI diagnosis. Note that this action was coded as a planning, rather than a compensatory, activity because the participant indicated that her job performance was not affected by her MCI symptoms, but she anticipated that it eventually would be.

Health Promotion Activities

Nearly one third ($n = 19$) of the 60 HRAs described by 33 participants fell into the category of health promotion. These activities included lifestyle changes to promote overall health status as well as behaviors that specifically targeted an individual's own health risk profile. Health promotion activities were further divided into three discrete subcategories: *physical activity*, *nutrition*, and *management of other health problems*. Participants' examples of physical activity were both general (e.g., exercise) and specific (e.g., triathlon training). As reflected in Table 2, health promotion also encompassed changes related to diet, vitamins or herbal remedies, which were grouped together under the subcategory of nutrition. As with physical activity, nutrition related activities were described with varying levels of specificity. An 81 year-old woman with 15 years of education reported herself to be "trying to eat better," while a 64 year-old man with 14 years of education described a concerted effort to minimize his sugar intake. The final subcategory of health promotion captured the efforts of persons with MCI to address other medical problems that they were experiencing, including those bearing a plausible relationship to MCI symptoms. Four participants described attending to such medical issues as obesity and sleep apnea, while two described more global efforts as evidenced by the following statement from a 68 year-old man with a high school education, "I am more faithful in following up in physical care, calling the doctor and go[ing] to see the doctor and be faithful in doing what they say to do."

General Activity

The third overarching category of HRAs comprises a range of efforts put forth to increase one's general activity level. Activities following into this category varied to include socialization, the pursuit of hobbies, and increased community involvement. Although numerous participants reported making efforts "stay active" or "keep busy," only six offered specific examples of new activities that they had initiated in order to meet this goal. An 80 year-old woman with a high school education stated, "I think my gardening helps. I

volunteer and I might do more of that.” A 66 year-old woman with 15 years of education reported, “[I] have started going back to church.”

Discussion

This interview-based study of health-related activities (HRAs) among persons recently diagnosed with MCI reveals affected individuals to engage in a wide range of behaviors to enhance or maintain their cognitive, physical, and psychosocial well-being. The most commonly adopted HRAs fall into the category of symptom-driven, followed by those behaviors oriented toward health promotion and then those aiming to more generally increase one’s activity level.

Our finding that cognitive stimulation was the most frequently reported subtype of symptom-driven HRAs cross validates prior research showing that mental exercises are the health behavior most viewed by those with MCI as protective against further cognitive decline (McIlvane et al., 2008). Additional evidence for this population’s preference for cognitively focused interventions is found in a report by Belleville and colleagues (2006) who noted a consistently high level of participation in a formal cognitive intervention program among persons with MCI. From a practice perspective, it is difficult to act upon this growing body of evidence that persons with MCI are receptive to cognitive interventions, because there are currently no clinical guidelines on the use of such interventions in MCI. Randomized controlled trials of cognitive stimulation interventions in MCI are limited and results from these studies, as well as from the normal aging and dementia literature, are mixed (Acevedo, & Loewenstein, 2007; Sitzler, Twamley, & Jeste, 2006; Wenisch et al., 2007), further contributing to clinical equipoise among those treating persons with MCI.

Regarding health behaviors more generally, recent research has shown that both asymptomatic (Chao et al., 2008) and symptomatic (McIlvane et al., 2008) persons in populations at risk for dementia are inclined to use dietary supplements and make other lifestyle changes based on knowledge of their heightened dementia risk status. Our findings inform this line of research in two key ways. First, responses to our open-ended question about self-initiated HRAs suggest the need to broaden the conceptualization of health behaviors in the context of MCI. For example, respondents in this sample were ensuring their health by taking safety precautions related to driving and medication administration. These are important undertakings to prevent negative health outcomes, but they are somewhat MCI-specific and do not generally appear on standard forced choice surveys of health behaviors. Second, findings from the current report suggest that, in addition to undertaking activities aiming to slow the progression of cognitive impairment, those with MCI also seek interventions focused on *current* cognitive symptom management. This finding has relevance for the emerging discourse on nonpharmacological interventions targeting MCI, which has to date focused almost exclusively on the secondary prevention of dementia. As outlined below, evaluating nonpharmacologic interventions for MCI, whether as symptom management or secondary prevention strategies, requires careful consideration of several conceptual and methodological issues.

Virtually all of the leading theories of health behavior would position the receipt of MCI diagnosis or experience of MCI symptoms as the impetus for engagement in HRAs such as those described in this report. Our group has previously introduced the application of the Common Sense Model of Illness Perception in the context of MCI (Lingler et al., 2006). This model holds that perceptions concerning the symptoms, cause, course, timeline, consequences, and controllability of a perceived threat to health (e.g., MCI) constitute a cognitive dimension of illness representation, and are processed in parallel with an

emotional dimension of illness representation. Cognitive and emotional representations of illness are posited to together drive behavioral responses to a perceived health threat (Leventhal et al., 1984). Unique features of this model include the notion of illness coherence (or, the clarity with which one understands a health threat) and emphasis on the emotional context in which illness perceptions are formed (Moss-Morris et al., 2008). Given the diagnostic ambiguity and prognostic uncertainty associated with MCI, a model which attends to illness coherence and gives equal weight to the cognitive and emotional dimensions of illness perception is especially appropriate. Emotions like fear and anxiety may partially explain the behavior of the above-described teacher who resigned from her position after learning of her MCI diagnosis. Focusing on preventative health behaviors, application of the Health Belief Model (Janz and Becker, 1984), would in contrast lead one to hypothesize that the primary driving force behind engagement in MCI-related HRAs is a combination of an individual's perceived susceptibility to, and views about the severity of, dementia. Based on these differences, the Common Sense Model of Illness Perception and Health Belief Model may suggest differing foci for psychoeducational interventions targeting those with MCI, with the former potentially placing greater emphasis on counseling and the latter giving more emphasis to education around dementia risk.

Alternatively, our study could be interpreted from the conceptual tradition of stress and coping (Lazarus & Folkman, 1984). Under this framework many of the HRAs articulated by this sample would constitute coping responses to the stress imposed by either the diagnostic label, or symptomatic manifestations, of MCI. In particular, the symptom-driven behaviors described herein align closely with what McIlvane and colleagues (2008) have characterized as problem-focused coping strategies in MCI. Of note, participants in this study did not specifically use the term "coping" to describe the actions that they had undertaken; nor did we use "coping" when posing our interview question. Nevertheless, most of the activities falling within the category of symptom-driven do represent practical strategies for managing the symptoms of MCI. As discussed above some participants in our sample reported going beyond the adoption of routine coping strategies to make major life changes, like taking an early retirement, after being diagnosed with MCI. Given that 1) MCI is, by definition, not associated with functional impairment (Petersen et al., 1999), and 2) not all persons diagnosed with MCI progress to dementia (Bruscoli & Lovestone, 2004), a measure such as early retirement from teaching may be viewed as a relatively extreme response to an MCI diagnosis. Under a stress and coping framework, early retirement (in the absence of impaired job performance) could be construed as behavioral disengagement, a form of dysfunctional coping.

Finally, this report highlights several methodological challenges to the study of nonpharmacological approaches to caring for patients with MCI. Many participants in this study were engaged in multiple activities which may have an effect on their symptom experience or disease course. Controlling for exposure to such a wide variety of interventions poses a challenge to the research process, especially considering the possibility of additive effects resulting from simultaneous engagement in multiple activities. Further complicating the study of behavioral interventions for MCI, some of the activities described herein have been posited or shown to have both immediate and long-term effects on multiple inter-related aspects of well-being. For example, Logsdon and colleagues (2009) have piloted an exercise program for persons with MCI and found the intervention to positively impact on participants' cognitive, physical and emotional well-being (Logsdon, McCurry, Pike, & Teri, 2009). Interventions with the potential for more diffuse or global effects on well being raise important questions about the selection of the most appropriate outcome for nonpharmacologic studies targeting the MCI population.

Limitations

Participants in the current sample were primarily Caucasian Americans with relatively high levels of education who had access to an ADRC. Data on HRAs were generated from chart review and responses to a single question about behaviors adopted following the MCI diagnosis. This study did not include measures of personality, spirituality, or locus of control, each of which may potentially explain why some individuals did not self-initiate HRAs. These limitations underscore the need to treat findings from this brief report as preliminary. More in-depth questioning of a purposively derived diverse sample is needed, especially considering our findings of minimal engagement in spiritual healing, complementary and alternative therapies.

Conclusion

Following a diagnosis of MCI, patients self-initiate a wide range of health related activities including engagement in symptom-driven behaviors, health promotion activities, and more general increases in social and leisure activities. Through this study we have a new understanding of what types and combinations of activities are being undertaken by this population at heightened risk for dementia. This information may directly inform the development of nonpharmacological interventions with particular appeal to persons with MCI. Future research should address the need for interventions not only to slow the progression of MCI, but also to minimize the immediate symptom experience of those affected.

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Table 1

Sociodemographic and Clinical Characteristics of Persons with MCI Initiating and Not Initiating Health-Related Activities

Characteristic	Initiating Health-Related Activities		t or χ^2 (df)	p
	Yes (n=33)	No (n=20)		
Gender, female	14	7	0.29 (1)	.243
Ethnicity, Caucasian	31	18	--	.627*
Age, in years	69 (9.3)	74 (8.1)	1.91 (51)	.060
Marital status, married	25	16	0.13 (1)	.721
Education, in years	16 (2.7)	15 (2.9)	-1.71 (51)	.090
MCI type, amnesic	27	15	0.35 (1)	.553
Global cognition (Folstein MMSE)	28 (2.1)	27 (2.4)	-1.14 (51)	.261
Depressive symptoms (Hamilton DRS)	5 (4.6)	3 (3.1)	-1.62 (51)	.111

Note:

MMSE = Mini-Mental Status Exam; DRS = Depression Rating Scale;

* Fisher's Exact Test

Table 2

Self-Initiated Health-Related Activities

Activities	Examples
I. Symptom-Driven Behaviors	
Cognitive stimulation	Taking classes, reading Playing bridge, Sudoku, word searches
Compensatory activities	Using calendars, lists, and written reminders Making word associations to jog memory
Safety and planning activities	Reducing or paying more attention when driving Involving others in management of medications and decision-making Conducting financial, end of life and other medico-legal planning for the future
II. Health Promotion Activities	
Physical Activity	Walking, Yoga, working out at a gym
Nutrition	Eating "healthy" (general statement) Reducing consumption of sugar and alcohol Taking vitamins or herbal supplements
Other Health Maintenance	Smoking cessation, weight loss Better adhering to prescribed medications Pursuing sleep apnea evaluation
III. Increasing General Activity Level	
	Staying busy Pursuing hobbies (trains, gardening, woodworking, travel) Socializing