Published in final edited form as:

J Neurosci Nurs. 2011 December ; 43(6): 317–328. doi:10.1097/JNN.0b013e318234e9dd.

Content Validity and Acceptability of the Daily Enhancement of Meaningful Activity Program Intervention for Mild Cognitive Impairment Patient-Spouse Dyads

Yvonne Yueh-Feng Lu, PhD, RN and Joan E. Haase, PhD, RN, FAAN
Indiana University School of Nursing

Abstract

Persons with mild cognitive Impairment (PwMCI) are at greater risk for developing Alzheimer's disease and they experience various difficulties that decrease their quality of life. Very few interventions focus on helping PwMCI improve or maintain functional performance and enhance quality of life through meaningful activity engagement. The purpose of the study was to explore PwMCI and their spouses' perspectives on the content validity, usefulness, and acceptability of the daily enhancement of meaningful activity (DEMA) program, which included 6 bi-weekly face-to-face sessions, between session assignments, and a self-management tool kit of written educational handouts. Nine PwMCI-care partner dyads participated in three focus groups (PwMCI alone, spouses alone, couples) to capture their perspectives on DEMA. The transcribed focus group data were analyzed through content analysis. The three groups provided support for content validity and acceptability of the program, and they suggested additional content areas important to couples experiencing MCI. They also attested to the usefulness of the tool kit and gave suggestions for its further improvement. The findings provide evidence of the content validity and acceptability of the DEMA program. A pilot study to assess feasibility and preliminary efficacy of the DEMA on health-related outcomes is the recommended next research step for this program.

Keywords

patient care partner; mild cognitive impairment; acceptability of program; program evaluation

Introduction

Mild cognitive impairment (MCI) is one of the most prevalent age-related disorders, affecting one fifth of the elderly population. Persons with MCI (PwMCI) are at increased risk for developing Alzheimer's disease (AD) (Busse, Bischkopf, Riedel-Heller, & Angermeyer, 2003; Unverzagt et al., 2007). Community- and population-based studies indicate that MCI progresses to dementia at a very high rate, from 13–48% over 12–60 months (Bennett, Schneider, Bienias, Evans, & Wilson, 2005; Busse, et al., 2003; Prncipe et al., 2003; Unverzagt et al., 2001)

Although PwMCI do not have full-blown dementia and do not experience the same level of difficulty, they do experience many difficulties that decrease their quality of life, including significant conflict in their relationships, depressed mood, decreased engagement in daily activities, and reduced ability to engage in complex daily activities (Apostolova & Cummings, 2008; Perneczky, Pohl, Sorg, Hartmann, Tosic, et al., 2006). PwMCI may be unaware of their deficits such as financial management or driving skills that place themselves at risk and also cause stress and conflict with their family members. In addition, family caregivers may inaccurately judge the MCI patient's function or awareness of performance capacity's (Clare, 2004; Laurin, Verreault, Lindsay, MacPherson, &

Rockwood, 2001; Okonkwo et al., 2009; Wadley et al., 2009). This misunderstanding can contribute to increased conflict in the relationship and contribute. It may also result in a decline in the MCI patient's quality of life because the patient realizes that his family believes him or her to be incapable. Spouses of PwMCI also experience quality-of-life problems, including relational deprivation, communication difficulty, and emotional distress associated with the cognitive deficits of patients (Austrom & Lu, 2009; Garand, Dew, Urda, Lingler, DeKosky, & Reynolds, 2007; Lu, Hasse, & Farran., 2007). Findings from a systematic review of literature indicate that cognitive training interventions are increasingly available (Jean, Bergeron, Thivierge, & Simard, 2010), most of which focus on the performance of memory tests, driving capability (Edwards et al., 2009) and psychological well-being (Apostolova & Cummings, 2008; Belleville, 2008; Bolleville et al., 2006; Kinsella et al., 2009; Troyer, Murphy, Anderson, Moscoritch, & Craik, 2008). One large randomize trial study showed that cognitive training, speed process of training, improves cognitive ability and less functional decline in instrument daily activities in well-functioning older adults (Willis et al., 2006). Even with progressive memory loss, interventions that are delivered early can assist PwMCI to communicate effectively with their spouses, and deal with memory loss problems affecting their activities of daily living. Such interventions have the potential of fostering physical and psychosocial well-being, prolonging functional independence, and decreasing costs (Jack et al., 2011). Though behavioral intervention have been evaluated for patients with dementia (Podewils, Guallar, Kuller, Fried, Lopez, Carlson, et al., 2005; Tappen, Roach, Applegate, & Stowell, 2000; Teri et al., 2003; Vance, Moore, Farr, & Struzick, 2008), very few interventions focus on helping PwMCI improve or maintain functional performance or enhance quality of life through meaningful activity engagement and few have specifically targeted the intertwined needs of the patient-caregiver dyad.

Daily meaningful activities are defined as activities that an individual finds important and enjoyable, ranging from the simple satisfaction derived from small daily rituals to the intense pleasure people feel in pursuing their driving passions (Kielhofner, 2002). These meaningful daily activities may include physical, cognitive, social, and leisure activities (Jedrzejewski, Lee, & Trojanowski, 2007; Larson et al., 2006; Verghese et al., 2006). PwMCI and their family members experience significant challenges in coping with problems, adjusting to changes, and planning for the future (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005; Garand, et al., 2007; Lu et al., 2007; Lu & Haase, 2009). Since PwMCI desire to preserve their ability to perform daily meaningful activities(Lu et al., 2007), have greater awareness of their limitations, and possess greater learning ability than patients with Alzheimer's Disease (Roberts, Clare, & Wood, 2009), earlier stages of cognitive decline offer an important window of opportunity to provide behavioral interventions to develop important self-management skills that will prevent premature disability and disengagement. Tailored interventions delivered to PMCI-family member (e.g., care partner) dyads at the earliest stage of cognitive impairment might have potential for being effective.

In this paper the authors describe the evaluation of the Daily Enhancement of Meaningful Activity (DEMA) intervention by 3 focus groups: PwMCI only, care partner only, and couples, (i.e., PwMCI and spouses combined). The purpose of the study was to explore the participants' perspectives on the content validity, usefulness, acceptability, and feasibility of the DEMA written educational materials, the DEMA program, and the program delivery format. The focus groups not only contributed to the refinement of the DEMA program and educational written materials; they also provided insights into the kind of help that PwMCI and their spouses need and want and the degree to which intervention components and design features are seen as helpful, acceptable, and feasible by PwMCI and their spouses.

Description of DEMA

DEMA was designed as a tailored skill-training program that aims to help couples facing MCI learn ways to supportively work together to meet goals and learn ways to adapt to changes that might occur over time. Content for DEMA was derived from several sources: 1) the Occupational Performance Model (Kielhofner, 2002) and problem solving therapy (Barrett et al., 1999) for content regarding identifying and planning meaningful activities; 2) literature review (Department of Health and Human Service, 2010; Lehmann, Regland, Blennow, & Gottfries, 2003; Mann et al., 2004; Mayo Clinic, 2008; U.S.; Okonkwo, Waldley, Griffith, Ball, & Marson, 2006; Perneczky et al., 2006; Petersen, 2007; Petersen et al., 2001; Podewils et al., 2005; Rejeski et al., 2009; Rosenberg, Kottorp, Winblad, & Nygard, 2009; Rovner, Casten, Leiby, & Tasman, 2009) and the American Alzheimer Association website for content on MCI diagnosis, symptoms, and treatments (Alzheimer Association, 2009); and 3) a qualitative study of MCI couples' experiences of living with MCI for content on emotional responses to MCI and guidelines for dealing with/living with MCI as a couple (Lu & Haase, 2009; Lu et al., 2007). Prior to obtaining perspectives of DEMA from focus group participants, the intervention was evaluated and refined based on feedback related to content validity, face validity, feasibility, and acceptability from an expert panel of six scientists/clinicians (expertise in neurology, geriatric medicine, geriatric nursing, health behavior) as well as, from and three other experts (the director of the local Alzheimer's Association, a medical visual media designer, and an experienced format designer) feedback.

The outcome of the expert panels was a DEMA intervention designed for delivery in 6 bi-weekly, one-hour, face-to-face sessions respectively focusing on 6 self-management needs: 1) planning meaningful activity, 2) understanding MCI, 3) understanding the treatment of mild cognitive impairment, 4) understanding and dealing with negative emotional responses, 5) learning strategies for living with MCI and dealing with major concerns, and 6) finding available local and national resources. The 6 sessions were planned for delivery by an advanced practice nurse intervener. Content for Session 1 focused on introducing the couple to the intervention and meaningful activity concepts, reviewing the PwMCI's history of meaningful activity, establishing a realistic and manageable meaningful activity plan, and introducing the 6 areas for counseling topics. The couple then set goals and developed a plan for activities that they considered important and meaningful; during the two weeks between sessions, participants worked on the agreed-upon goals and activities, either as a couple, as the PwMCI, or as the care partner. In Sessions 2 to 6, the first 30–40 minutes focused on the specific meaningful activity that had been planned during the previous session and included: a) assessing any concerns that might have occurred related to the planned activity engagement; b) reviewing the nature and frequency of existing meaningful activity patterns; c) using problem-solving to assess the current week's activity plan and making any necessary modifications; d) identifying ways of maintaining meaningful activity engagement. Guided by the Self-management Tool Kit, the last 20–30 minutes focused on 1 of the 6 counseling topics (see Table 1). The tool kit is organized around the 6 self-management needs, and consists of 40 subtopic handouts. For each session, between 5 and 8 subtopic handouts were available to the couple to help structure the face-to-face sessions (see Table 2).

Methods

Three focus groups were conducted to capture, respectively, the perspectives of the PwMCI, spouses, and couples on DEMA. Specifically, the focus groups assisted in evaluation of the content validity and acceptability of the Self-management Tool Kit, the DEMA intervention content, the intervention format, and the barriers to using the program among PwMCI and their spouses.

Sample and Setting

A convenience sample was obtained through clinics associated within the Indiana University (IU) Health Care System, specifically the University Hospital neurology clinics, the IU Alzheimer Center, and the IU Healthy Aging Brain Center. To be enrolled in the study, both the PwMCI and the care partner had to consent. In each setting, participants were first approached by the professional staff to ascertain interest in participating. Focus group participants were those PwMCI who had been officially diagnosed at least 6 months prior to study enrollment and their care partner. Inclusion criteria required persons with MCI to be English-speaking adults, aged 60 or older, who had a medical diagnosis of MCI for at least 6 months. The diagnosis of MCI was made on the basis of clinical examination by the geriatric neurologist and/or neuropsychologist, using criteria consistent with the guidelines established by Petersen and colleagues (Petersen et al., 1999). Inclusion criteria of care partners required that they be English-speaking adults, identified by the PwMCI as their primary care partner. All the care partners identified by the PwMCI were spouses. Of the 20 couples identified, 6 did not meet the recruitment criteria. Of the remaining 14 couples, 5 (35.71%) declined participation and 9 (64.29%) consented to participate and were enrolled in the focus groups. The reasons for choosing not to participate were: either the PwMCI or spouse (but never both) was not interested ($n = 3$), scheduling conflicted with spouse's work ($n = 1$), and driving distance to attend the focus group was too far ($n = 1$).

Participant Characteristics

The accrued PwMCI sample ($n = 9$) included 7 males and 2 females, who were all Caucasian and retired. Their mean age was 68.9 years ($SD = 8.4$), mean education was 16.9 years ($SD = 2.47$), and time since diagnosis was 1.5 to 4.5 years ($M = 2.8$ years). The accrued spouse sample ($n = 9$) included 8 Caucasians (6 females, 2 males) and 1 female Asian American. Two of the PwMCI had received depression medication treatment for at least one month. The spouses' mean age was 65.1 ($SD = .97$) years and the mean education was 15.3 ($SD = 7.5$) years. Eight of the 9 couples were in their first marriage; one couple was in a second marriage. All reported their financial status as adequate to meet their needs; however, 1 of the 9 couples was concerned about their future financial status because of the economic recession in the U.S. Before retirement the PwMCI had primarily worked in the professional or business sector (engineer, manager, university professor, financial consultant, high school teacher, or secretary). Most spouses were retired and not working; one spouse was working in a full-time manager position, and two were working part-time as a secretary or in business.

Data Collection Procedure

In this IRB-approved study, the 9 couples who indicated interest in participating were contacted and given a more detailed description of the study. The signed consent forms were collected by mail at least one week prior to the focus group meeting or in person before the focus group meeting. For those couples who returned signed consent forms or had verbally agreed to participate, the meeting time and location were mailed along with a cover letter, a brief description of the program, and a copy of the most recent version of the Self-management Tool Kit at least one week prior to the focus group meeting. Couples were asked to read the program brief description and tool kit materials and to make notes about them as reminders of comments or questions they wished to raise during the focus group meetings.

The first round of focus group meetings was done simultaneously and separately for PwMCI ($n = 6$) and the spouses ($n = 6$). Each group was led by a certified focus group facilitator with a master's degree in social work. During the meetings, the facilitators solicited comments regarding relevance, clarity, and appropriateness of the content of the Self-

management Tool Kit and acceptability of intervention implementation, including the length, timing, and mode of delivery. The third focus group (3 couples) was held after revisions were made to DEMA based on feedback from the initial 2 groups. In this second round, three PwMCI-spouse dyads met with a certified focus group facilitator.

Data-generating Questions

To guide discussion and evaluate the content of the Self-management Tool Kit and DEMA program with the first two groups, we used a list of open-ended questions, with follow-up questions as needed. The questions were as follows. (1) In general, what do you think about the written material? (2) For each session, is there anything we should add or delete? (3) Regarding the written material, what was the most helpful information for you? (4) What was least helpful for you? (5) How relevant, clear, and appropriate is the material? (6) Are there any aspects of your life that have been affected by memory problems that are not covered? (8) Is there anything else you would like to let us know? (8) Do you think you could benefit from this program? Additional questions were asked regarding couples' preferences related to implementing the program, including recruitment strategies; location, schedule, duration and frequency of intervention; and preferences for individual, small group, telephone, or online delivery method.

The list of open-ended questions for the third focus group, was the same as for the first two. Additionally, this group was asked to provide more detailed information on the usefulness and acceptability of program implementation. The third focus group was also asked to provide comments on the content of the Self-management Tool Kit based on the revisions from the initial 2 groups. At the end of all focus groups meetings, participants were asked to return their written comments (if any) to the investigators.

Analysis

The transcribed focus group data were analyzed by two nurse scientists using content analysis methods (Miles & Huberman, 1994). The significant statements were identified from data obtained from each focus group and initially categorized by using a predetermined start list addressing the acceptability domains (e.g., most helpful and least helpful content, comprehensibility and adequacy of content, acceptability of the intervention format [length and duration of program, frequency of meeting sessions, meeting location, and schedule]). The significant statements were organized into theme categories. The researchers also compared the congruence and differences in coding of significant statement data across the three focus groups. The researchers discussed differences in the coding of significant statements until 100% agreement was reached. The resulting categories were used to narratively describe findings. Seven sub-themes were developed: What the couple wants in the intervention; self-management; communication skills; technology needs; emotional management; program implication; and recruitment strategy.

Results

The following is a summary of the findings related to face validity and acceptability of DEMA. Participants' views were solicited about the Tool kits, intervention format, content evaluation, and recommendations for improving the intervention protocol and Tool Kit.

Focus Group Comments

Overall, participants' perceived the content as adequate, clear, and easy to follow and understand. The ordering of the sessions was deemed appropriate by the couples. Couples indicated that Session 1, planning daily meaningful activity, helped them to positively focus on individual strengths, health promotion, and remaining "hopeful" rather than focusing on

deficits. Couples also agreed that having session objectives raised their level of interest in and attention to the main topics of the session.

All groups provided insightful comments on the tool kit components and specified the most helpful tool kit components and mechanisms. For example, the all 3 groups indicated that the handout on examples of meaningful activities was very helpful because it not only reinforced meaningful activities they had done before; use of the weekly plan also guided them to again initiate these and other activities in practical and manageable ways. The PwMCI and spousal groups agreed that the topic of negative emotional responses helped them better deal with such responses. The handout on living with MCI was helpful for PwMCI to manage their challenges, and the spousal group indicated it would be a useful tool to open discussion with PwMCI and other family members. Notably, the handout on resources regarding medications and finding a good attorney was highly accepted by the spousal group, although it was not mentioned by either the PwMCI or the couple group. The advantage of having the three types of focus groups is that the results showed there were some topics (e.g., finding a good attorney) the spouses probably did not want to discuss in front of the patients.

Each group offered explicit comments on the intervention format and content-sensitive issues. The spousal group had several suggestions, including: eliminating all abbreviations on written materials; providing brief and clear definitions of medical terms; using a large font size; and keeping content simple and easy to understand. The Self-management Tool Kit was designed for both PwMCI and their spouse to use together, but spouses preferred to have their own tool kit with more advanced information. In addition, the couples preferred to attend the program together in order to gain understanding and improve communication with each other. The PwMCI and couple groups emphasized the importance of including clear objectives for each session, because this helped them understand and stay focus on each session. Interestingly, the spouse and couple groups made several comments and suggested modifications regarding content sensitivity, but the PwMCI group did not focused these issues. For example, spouses of PwMCI disliked being called “caregiver” and preferred being called “husband/wife,” “care partner,” or “supporter” because they viewed themselves in these ways. The spouses also raised gender sensitivity issues related to types of housework, such as that cleaning and laundry are not men’s works. They also disliked certain terms of emotional distress such as “grief” and “isolation,” and they suggested alternate terms such as “feeling sorrow” and “being alone.”

Table 3 contains a summary of the four main areas that participants thought should be included in the program: self-management, communication skills, technology needs, and emotional management. The groups recommended establishing useful self-management tips, such as how to organize household items to help PwMCI perform their activities independently. Improving communication skills was also one of the participants’ primary needs. For example, PwMCI wanted to learn ways to tell their spouse not to overprotect them, and spouses wanted tips on telling other family members or close friends about their memory problems and how to encourage PwMCI to stop potential harmful activity such as using an electric saw for cutting trees. It is interesting to notice that managing emotional distress and training in the use of technology-assisted devices training were raised by the PwMCI and spouse groups. For example, they agreed that depression was a common occurrence that should be addressed. The PwMCI also recommended providing information and training, as well as specific modification, on technology-assisted devices, especially Global Positioning Systems (GPS) and mobile phones.

Table 3 also shows the comments on the program format, such as program dosage, schedule, meeting location, and delivery. The program dosage plan, which included bi-weekly

meetings for a total of 6 sessions with 1 hour for each session, was acceptable to all three focus groups, except several working spouses who did not have a regular working schedule. Additionally, the spousal and couples groups recommended the following: (a) flexibility with scheduling; (b) a delivery site at the clinic or participant's home; and (c) meeting on weekday mornings, but late enough to avoid rush hour driving. Having program delivery in small groups was suggested by the spousal group, thought not by PwMCI. Both PwMCI and spouses agreed that the best recruitment strategy was physicians' referral, but other strategies could be considered such as advertisements in local newspapers, TV, or radio. Finally, the main reasons for research participation were: to make a "contribution" for other PwMCI and their family members, to gain knowledge about MCI and its treatment, and to learn coping and caregiving skills.

Discussion

It was important to establish evidence of the content validity and acceptability of this newly developed intervention from both the PwMCI and spouses' perspectives. The three focus groups (PwMCI, spouses, and couples) provided important comments and specific recommendations on the revision of the DEMA program format and the content of the Self-management Tool Kit. The focus group participants not only provided support for content validity and acceptability of the DEMA program; they also recommended additional content areas important to couples experiencing MCI such as having positive experiences of using GPS to minimize incorrect driving directions and arguments while the PwMCI was driving. The PwMCI focus group believed it would be useful to provide information and training on technology-assisted devices, and they gave specific suggestions for improvement of the handouts in this area.

Consistent with past research (Farias et al., 2006; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008), PwMCI recognized that they needed help with executive functioning-related activities such as taking phone messages and organizing medication. They did not feel the need for help with basic daily living activities, since they were able to select their own clothing, bathe themselves, feed themselves, and walk around the neighborhood. In addition, similar to other descriptive studies, the authors found that PwMCI perceived greater difficulty in using technology than healthy older adults (Rosenberg, et al., 2009) and wanted brief training from locally available resources in order to use technology devices (e.g., GPS or mobile phone). Since they considered mobile phones to be quite useful, offering advice on models with larger button and display sizes, and providing simplified manuals should be considered for future study (Mann, et al., 2004).

Similar to previous studies, PwMCI and their spouses showed a great deal of interest in health promotion activities (engaging in meaningful activities or brain exercises) for preserving independent functioning or decreasing the limitations associated with the progress of memory problems (McIlvane, et al., 2008). Although changes in the underlying functional impairment are difficult to achieve, the impact of impairment in daily activity or meaningful activity engagement may be mediated by training in compensatory strategies.

Even though the spousal group did not currently feel the need for help to use local or national resources for activities such as home repair/maintenance, adult day services, or home-delivered meals, they thought they might need such resources in the future. The degree to which both the PwMCI and the spouse groups indicated the desire and need for knowledge about GPS was interesting. A previous study suggested that global positioning system (GPS) technology may be able to provide further information about driving patterns among older adults (Marshall et al., 2007).

Since PwMCI are eager to learn new skills and could be taught how to use strategies to adjust activities and to manage emotional distress such as depression that might be associated with MCI (Troyer, et al., 2008), they might be able to apply problem-solving therapy skills to overcome these challenges. Current clinical trial studies have shown that problem-solving therapy is effective in reducing emotional distress and depression among older adults with MCI (Kiosses, rean, Teri, & Alexopoulos, 2010). In addition, consideration should be given to providing training on GPS and cell phones to maintain or improve functioning performance.

The focus group showed that spouses had needs for information and for acquiring skills to improve communication and manage emotional distress, suggesting that it is important to provide early intervention to assist PwMCI and/or family members to gain self-management skills that could influence PwMCI behavior (de Vugt et al., 2004). The findings also support the importance of integrating family members into interventions designed for PwMCI, because it provides a foundation of support as family members move to a greater caregiving role in response to the progression to Alzheimer's disease, which was also reported by Brodaty et al (Brodaty, Green, & Koschera, 2003).

Recruitment Issues

Like the other community studies for older adults (Blumenthal, Coates, Williams, & Liff, 1995; Cohen-Mansfield, 2002), the recruitment of PwMCI-family member dyads and minorities for the focus groups was a challenge, especially when the study offered no immediate therapeutic benefit. Similar to other studies, the most common reasons for refusal to participate were: not interested (or denying having memory problems) and conflict with spouse's work schedule (Dilworth-Anderson, Thaker, & Detry Burke, 2005; Shatenstein, Kergoat, & Reid, 2008). The DEMA might not be useful to those unwilling to admit any problems, because the DEMA depends on being willing to acknowledge and discuss problems. Since the pilot study relied on referrals and on the match between the referral and the inclusion criteria, relaxing some exclusion criteria could be considered in order to improve recruitment in the future (e.g., being able to recruit non-spouse adult family members and unpaid caregivers).

Limitations

Generalizability of the findings from this study is limited due to having a small sample size that lacked minority participants. Although the sample size was small, it was adequate for examining content validity and acceptability of a new intervention for non-minority participants (Arnold et al., 2009; Lancaster, Dodd, & Williamson, 2004). In addition, only spouses were included; adult children who are care partners may have different perspectives. The authors recommend that further research be conducted on the efficacy of DEMA using larger and more diverse samples.

Conclusions

Establishing evidence of the content validity and acceptability for a new intervention is very important before conducting large clinical trials to evaluate efficacy. The findings of this study provide preliminary evidence of the content validity and acceptability of the DEMA program. Future research is needed to test the feasibility and effectiveness of the DEMA on health-related outcomes with a larger sample that compares the intervention group to a control group. If the DEMA program is shown to be valid and effective, testing the effectiveness of a telephone-based or web-based DEMA program should also be considered, to potentially reach a broader and more diverse population of PwMCI and their family members, to improve their emotional well-being, maintain/improve functioning, and improve quality of life.

References

- Alzheimer's, Association. Fact sheet: Mild cognitive impairment (MCI). 2009. Retrieved April 27, 2009, from http://www.alz.org/alzheimers_disease_mild_cognitive_impairment.asp
- Apostolova LG, Cummings JL. Neuropsychiatric manifestations of mild cognitive impairment: A systematic review of the literature. *Dement Geriatric Cognitive Disorder*. 2008; 25(1):115–116.
- Arnold DM, Burns KEA, Adhikari NKJ, Kho ME, Meade MO, Cook DJ. The design and interpretation of pilot trials in clinical research in critical care. *Critical Care Medicine*. 2009; 37(1 suppl):S69–S74. [PubMed: 19104228]
- Austrom MG, Lu YF. Long term caregiving: Helping families of persons with mild cognitive impairment cope. *Current Alzheimer Research*. 2009; 6(4):392–398. [PubMed: 19689239]
- Barrett JE, Williams JW Jr, Oxman TE, Katon W, Frank E, Hegel MT, Schulberg HC. The treatment effectiveness project. A comparison of the effectiveness of paroxetine, problem-solving therapy, and placebo in the treatment of minor depression and dysthymia in primary care patients: background and research plan. *General Hospital Psychiatry*. 1999; 21(4):260–273. [PubMed: 10514950]
- Belleville S. Cognitive training for persons with mild cognitive impairment. *International Psychogeriatrics*. 2008; 20(1):57–66.
- Bennett DA, Schneider JA, Bienias JL, Evans DA, Wilson RS. Mild cognitive impairment is related to Alzheimer disease pathology and cerebral infarctions. *Neurology*. 2005; 64(5):834–841. [PubMed: 15753419]
- Blumenthal DS, Coates R, Williams J, Liff J. Mounting research addressing issues of race/ethnicity in health care. *Health Services Research*. 1995; 30(1):197–205. [PubMed: 7721592]
- Bolleville S, Gilbert B, Fontaine F, Cagnon L, Menard E, Gauthier S. Improvement of episodic memory in persons with mild cognitive impairment and health older adults: Evidence from a cognitive intervention program. *Dementia Geriatric Cognitive Disorder*. 2006; 22(5–6):486–499.
- Brodsky H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*. 2003 May; 51(5):657–64. [PubMed: 12752841]
- Busse A, Bischoff J, Riedel-Heller SG, Angermeyer MC. Subclassifications for mild cognitive impairment: prevalence and predictive validity. *Psychological Medicine*. 2003; 33(6):1029–1038. [PubMed: 12946087]
- Clare L. Awareness in early-stage Alzheimer's disease: A review of methods and evidence. *The British Journal of Clinical Psychology*. 2004; 43(Pt 2):177–196. [PubMed: 15169617]
- Cohen-Mansfield J. Recruitment rates in gerontological research: The situation for drug trials in dementia may be worse than previously reported. *Alzheimer Disease & Associated Disorders*. 2002; 16(4):279–282. [PubMed: 12468903]
- de Vugt ME, Stevens F, Aalten P, Lousberg R, Jaspers N, Winkens I, Verhey FR. Do caregiver management strategies influence patient behaviour in dementia? *International Journal of Geriatric Psychiatry*. 2004; 19(1):85–92. [PubMed: 14716704]
- Dilworth-Anderson P, Thaker S, Detry Burke JM. Recruitment strategies for studying dementia in later life among diverse cultural groups. *Alzheimer Disease & Associated Disorders*. 2005; 19(4):256–260. [PubMed: 16327355]
- Edwards JD, Myers CM, Ross LA, Roenker DL, Cissell GM, McLaughlin AM, Ball KK. The longitudinal impact of cognitive speed of processing training on driving mobility. *The Gerontologist*. 2009; 49(4):485–494. [PubMed: 19491362]
- Farias ST, Mungas D, Reed BR, Harvey D, Cahn-Weiner D, DeCarli C. MCI is associated with deficits in everyday functioning. *Alzheimer Disease Associated Disorder*. 2006; 20:217–223.
- Garand L, Dew MA, Eazor LR, DeKosky ST, Reynolds CF 3rd. Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *International Journal of Geriatric Psychiatry*. 2005; 20(6):512–522. [PubMed: 15920711]
- Garand L, Dew MA, Urda B, Lingler JH, DeKosky ST, Reynolds CF III. Marital quality in the context of mild cognitive impairment. *Western Journal of Nursing Research*. 2007; 29(8):976–992. [PubMed: 17984481]

- Jean L, Bergeron M, Thivierge S, Simard M. Cognitive intervention program for individuals with mild cognitive impairment: Systematic review of the literature. *American Journal Geriatric Psychiatry*. 2010; 18(4):281–296.
- Jack, JrCR.; Albert, MS.; Knopman, DS.; McKhann, GM.; Sperling, RA.; Carrilo, MC.; Phelps, CH. Introduction to the recommendations from the National Institute on Aging and the Alzheimer's Association workgroup on diagnostic guidelines for Alzheimer's disease. *The Journal of the Alzheimer's Association: Alzheimer's & Dementia*. 2011; 7:1–6. (in press).
- Jedrzejewski MK, Lee VMY, Trojanowski JQ. Physical activity and cognitive health. *The Journal of the Alzheimer's Association: Alzheimer's & Dementia*. 2007; 3(2):98–108.
- Kielhofner, G. *The model of human occupation: Theory and application*. Baltimore, MD: Lippincott Williams & Wilkins; 2002.
- Kinsella GJ, Mullaly E, Rand E, Ong B, Burton C, Price S, Storey E. Early intervention for mild cognitive impairment: A randomized clinical trial. *Journal of Neurology Neurosurgery & Psychiatry*. 2009; 80(3):730–736.
- Kiosses DN, rean PA, Teri L, Alexopoulos GS. Home-delivered problem adaptation therapy (PATH) for depressed, cognitively impaired, disabled elders: A preliminary study. *American Journal of Geriatric Psychiatry*. 2010
- Lancaster GA, Dodd S, Williamson PR. Design and analysis of pilot studies: recommendations for good practice. *Journal of Evaluation in Clinical Practice*. 2004; 10(2):307–312. [PubMed: 15189396]
- Larson EB, Wang L, Bowen JD, McCormick WC, Teri L, Crane P, Kukull W. Exercise is associated with reduced risk for incident dementia among persons 65 years of age and older.[see comment] [summary for patients in *Ann Intern Med*. *Annals of Internal Medicine*. 2006; 144(2):73–81. [PubMed: 16418406]
- Laurin D, Verreault R, Lindsay J, MacPherson K, Rockwood K. Physical activity and risk of cognitive impairment and dementia in elderly persons. *Archives of Neurology*. 2001; 58(3):498–504. [PubMed: 11255456]
- Lehmann M, Regland B, Blennow K, Gottfries CG. Vitamin B12-B6-folate treatment improves blood-brain barrier function in patients with hyperhomocysteinaemia and mild cognitive impairment. *Dementia & Geriatric Cognitive Disorders*. 2003; 16(3):145–150. [PubMed: 12826740]
- Londos E, Boschian K, Liden A, Persson C, Minthon L, Lexell J. Effects of a goal-oriented rehabilitation program in mild-cognitive impairment: A pilot study. *American Journal of Alzheimer's Disease & Other Dementia*. 2008; 23(2):177–183.
- Lu Y-F, Haase JE. Perspective of Experience of Being Caregivers of Spouse with Mild Cognitive Impairment. *Current Alzheimer Research*. 2009; 6(4):3384–3391.
- Lu YF, Haase JE, Farran CJ. Perspectives of persons with mild cognitive impairment: Sense of being able. *Alzheimer's Care Quarterly*. 2007; 8(1):45–86.
- Mann W, Helal S, Davenport RD, Justiss MD, Tomita MR, Kemp BJ. Use of cell phones by elders with impairments: Overall appraisal, satisfaction, and suggestions. *Technology and Disability*. 2004; 16(1):49–57.
- Mayo Clinic, C. Mild Cognitive Impairment. 2008. <http://www.mayoclinic.com> Retrieved June 1, 2008
- McIlvane JM, Popa MA, Robinson B, Houseweart K, Haley WE. Perceptions of illness, coping and well-being in persons with mild cognitive impairment and their care partners. *Alzheimer Disease & Associated Disorders*. 2008; 22(3):284–292. [PubMed: 18580593]
- Miles, M.; Huberman, AM. *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage; 1994.
- Okonkwo OC, Griffith RH, Vance DE, Marson DC, Ball KK, Wadley VG. Awareness of Functional Difficulties in Mild Cognitive Impairment: A Multi-Domain Assessment Approach. *Journal of American Geriatric Society*. 2009; 57(6):978–984.
- Okonkwo OC, Wadley VG, Griffith HR, Ball K, Marson DC. Cognitive correlates of financial abilities in mild cognitive impairment. *Journal of American Geriatric Society*. 2006; 54:1745–1750.

- Perneckzy R, Pohl C, Sorg C, Hartmann J, Tosic N, Grimmer T, Kurz A. Impairment of activities of daily living requiring memory or complex reasoning as part of the MCI syndrome. *International Journal of Geriatric Psychiatry*. 2006; 21(2):158–162. [PubMed: 16416470]
- Petersen RC. Mild Cognitive Impairment. *Continuum Lifelong Learning Neurology*. 2007; 13(2):15–38.
- Petersen RC, Doody R, Kurz A, Mohs RC, Morris JC, Rabins PV, Winblad B. Current concepts in mild cognitive impairment. *Archives of Neurology*. 2001; 58(12):1985–1992. [PubMed: 11735772]
- Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E. Mild cognitive impairment: clinical characterization and outcome. *Archives of Neurology*. 1999; 56(3):303–308. [PubMed: 10190820]
- Podewils LJ, Guallar E, Kuller LH, Fried LP, Lopez OL, Carison M, Laakso MP. Physical activity, APOE genotype, and dementia risk: Findings from the cardiovascular health cognition study. *American Journal of Epidemiology*. 2005; 161(7):639–651. [PubMed: 15781953]
- Prencipe M, Santini M, Casini AR, Pezzella FR, Scaladaferri N, Culasso F. Prevalence of non-dementing cognitive disturbances and their association with vascular risk factors in an elderly population. *Journal of Neurology*. 2003; 250:907–912.
- Rejeski WJ, Marsh AP, Chmelo E, Prescott AJ, Dobrosielski M, Walkup MP, Kritchevsky S. The lifestyle interventions and independence for elders pilot (LIFE-P); 2-year follow-up. *Journal of Gerontology: Medical Sciences*. 2009; 64(4):462–467.
- Roberts JL, Clare L, Wood RT. Subjective memory complaints and awareness of memory functioning in mild cognitive impairment: A systematic review. *Dementia and Geriatric Cognitive Disorders*. 2009; 28(2):95–109. [PubMed: 19684399]
- Rosenberg L, Kottorp A, Winblad B, Nygard L. Perceived difficulty in everyday technology use among older adults with or without cognitive deficits. *Scandinavian Journal of Occupational Therapy*. 2009; 16(1):1–11.
- Rovner BW, Casten RJ, Leiby BE, Tasman WS. Activity loss is associated with cognitive decline in aged-related macular degeneration. *Alzheimer's & Dementia*. 2009; 5(1):12–17.
- Rozzini L, Costardi D, Chilovi BC, Franzoni S, Trabucchi M, Pardovani A. Efficacy of cognitive rehabilitation in patients with mild cognitive impairment treated with cholinesterase inhibitors. *International Journal of Geriatric Psychiatry*. 2007; 22(4):356–360. [PubMed: 17117398]
- Shatenstein B, Kergoat MJ, Reid I. Issues in recruitment, retention, and data collection in a longitudinal nutrition study of community-dwelling older adults with early-stage Alzheimer's dementia. *Journal of Applied Gerontology*. 2008; 27(3):267–285.
- Tappen RM, Roach KE, Applegate EB, Stowell P. Effect of a combined walking and conversation intervention on functional mobility of nursing home residents with Alzheimer disease. *Alzheimer Disease & Associated Disorders*. 2000; 14(4):196–201. [PubMed: 11186596]
- Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner DM, Barlow WE, Larson EB. Exercise plus behavioral management in patients with Alzheimer disease: A randomized controlled trial. *JAMA*. 2003; 290(15):2015–2022. [PubMed: 14559955]
- Troyer AK, Murphy KJ, Anderson ND, Moscoritch M, Craik FL. Changing everyday memory behaviour in amnesic mild cognitive impairment: a randomised controlled trial. *Neuropsychological Rehabilitation*. 2008; 48(1):65–88. [PubMed: 17943615]
- Unverzagt FW, Gao S, Baiyewu O, Ogunniyi AO, Gureje O, Perkins A, Hendrie HC. Prevalence of cognitive impairment: data from the Indianapolis Study of Health and Aging. *Neurology*. 2001; 57(9):1655–1662. [PubMed: 11706107]
- Unverzagt FW, Gao S, Lane KA, Callahan C, Ogunniyi A, Baiyewu O, Hendrie HC. Mild cognitive dysfunction: An epidemiological perspective with an emphasis on African Americans. *Journal of Geriatric Psychiatry & Neurology*. 2007; 20(4):215–226. [PubMed: 18004008]
- Vance DE, Moore BS, Farr KE, Struzick T. Procedural memory and emotional attachment in Alzheimer disease: Implications for meaningful and engaging activities. *Journal of Neuroscience Nursing*. 2008; 40(2):96–102. [PubMed: 18481739]
- U.S. Department of Health and Human Services, National Institutes of Health (NIH), NIH Consensus Development Program. NIH State-of-the-Science Conference: Preventing Alzheimer's disease and

cognitive decline. (NIH AHRQ Publication No. 10-E005). 2010. Retrieved from http://consensus.nih.gov/2010/docs/alz/ALZ_Final_Statement.pdf

Verghese J, LeValley A, Derby C, Kuslansky G, Katz M, Hall C, Lipton RB. Leisure activities and the risk of amnesic mild cognitive impairment in the elderly. *Neurology*. 2006; 66(6):821–827. [PubMed: 16467493]

Wadley VG, Okonkwo O, Crowe M, Vance DE, Elgin JM, Ball KK, Owsley C. Mild cognitive impairment and everyday function: An investigation of driving performance. *Journal of Geriatric Psychiatry Neurology*. 2009; 22(2):87–94.

Willis SL, Tennstedt SL, Marsiske M, Ball K, Elias J, Mann K, Wright E. Long-term effects of cognitive training on everyday functional outcomes in older adults. *JAMA*. 2006; 296(23):2805–2814. [PubMed: 17179457]

Table 1**Daily Enhancement of Meaningful Activity (DEMA) Program Content**

Session No/Theme and Intervention Content
<p>Session I: Information/ Daily Meaningful Activity Values</p> <p>Part A:</p> <ul style="list-style-type: none"> • Review the program plan and goal. • Introduce the use of “DEMA: Self-management Tool Kit.” • Identify individual performance ability and deficits. • Open discussion on daily living values. • Explore individual meaningful activity engagement value. • Identify individual’s ability to engage in meaningful activities. • Review planning meaningful activity by using Self-management Tool Kit. <p>Part B:</p> <ul style="list-style-type: none"> • Discuss the main concerns related to overview of MCI and potential risk factors by using Self-management Tool Kit. • Suggest writing down at least one major concern or question for the next meeting.
<p>Session II: Individual Goal(s) and Meaningful Daily Living Preferences-1</p> <p>Part A:</p> <ul style="list-style-type: none"> • Identify level of congruency in individual performance ability. • Prioritize individual’s meaningful activities to address in order. • Try to reach agreement on targeting meaningful activity No. 1 by using problem-solving skills. • Set up individual manageable goals for targeting meaningful activity No. 1. • Identify the potential barriers to performing meaningful activity No. 1. • Brainstorm on solutions for targeting meaningful activity No. 1. <p>Part B</p> <ul style="list-style-type: none"> • Discuss the main concerns related to MCI treatment by using Self-management Tool Kit.
<p>Session III: Meaningful Daily Living Preferences-2</p> <p>Part A</p> <ul style="list-style-type: none"> • Use communication skills in evaluating failure and success in engaging in meaningful activity No. 1 and review problem-solving as needed. • Solicit feedback on the consequences of engaging in meaningful activity No1. • Try to reach agreement on meaningful activity No. 2. • Set up individual manageable goals for targeting meaningful activity No. 2. • Identify the potential barriers to perform meaningful activity No. 2. • Brainstorm on solutions for targeting meaningful activity No. 2. <p>Part B</p> <ul style="list-style-type: none"> • Discuss the main concerns related to managing emotional responses by using Self-management Tool Kit.
<p>Session IV: Meaningful Daily Living Preferences-3</p> <p>Part A</p> <ul style="list-style-type: none"> • Use communication skills in evaluating failure and success in engaging in meaningful activity No. 2 and review problem-solving as needed. • Solicit feedback on the consequences of engaging in meaningful activity No. 2. • Try to reach agreement for targeting meaningful activity No. 3. • Set up individual achievable goals for targeting meaningful activity No. 3.

Session No/Theme and Intervention Content	
Part B	<ul style="list-style-type: none"> Identify the potential barriers in performing meaningful activity No. 3. Brainstorm on the solutions for targeting meaningful activity No. 3.
	<ul style="list-style-type: none"> Discuss the main concerns related to guidelines for living with MCI and family members by using Self-management Tool Kit as needed.
Session V: Meaningful Daily Living Preferences-4	
Part A	<ul style="list-style-type: none"> Use communication skills in evaluating success and failure in engaging in meaningful activity No 3 and review problem-solving as needed. Solicit feedback or feelings on the consequences of engaging in meaningful activity No. 3. Try to reach agreement for targeting meaningful activity No. 4. Set up individual achievable goals for targeting meaningful activity No. 4. Identify the potential barriers in performing meaningful activity No. 4. Brainstorm on the solutions for targeting meaningful No. 4. Generate solutions and choose manageable solutions for targeting meaningful activity No. 4.
	<ul style="list-style-type: none"> Discuss the main concerns related to available local or national resources by using Self-management Tool kit as needed.
Session VI. Challenges and Final Review	
	<ul style="list-style-type: none"> Use communication skills in evaluating success and failure in engaging in meaningful activity No. 4 and review problem-solving as needed. Review and modify solutions for targeting meaningful activity No. 4 by using problem-solving skills. Review past discussions. Recognize unresolved issues. Modify solutions and find where to go to get the needed help.

Table 2

Self-management Tool Kit

Topic Handouts
<p>Session I: Planning Meaningful Activity</p> <ul style="list-style-type: none"> • Definition of meaningful activity • Benefits of meaningful activity engagement • Self-selecting meaningful activities • Planning meaningful activities for the coming week • Sample of weekly activity plan.
<p>Session II: Mild Cognitive Impairment Information</p> <ul style="list-style-type: none"> • Definition of MCI • Cause of MCI • Diagnosis of MCI • The progress of memory decline • Examples of other PwMCIs' experiences of awareness of memory changes
<p>Session III: Mild Cognitive Impairment Treatment</p> <ul style="list-style-type: none"> • Purpose of using medication • Individual response to medication • Medication dosage • Questions you should ask your doctor regarding medication • Treating cognitive symptoms • Treating other symptoms, e.g., depression.
<p>Session IV: Common Emotional Responses</p> <ul style="list-style-type: none"> • Part A: Emotional responses of PwMCI (e.g., shock, denial, anger, fear, uncertainty, isolation, sorrow, loss of control, depression) • Part B Emotional responses of family members (denial, anger, guilt, neglect, fear, isolation, sorrow, loss of freedom, depression)
<p>Session V: Guidelines for Living with Mild Cognitive Impairment</p> <ul style="list-style-type: none"> • Part A: Guidelines for PwMCI <ul style="list-style-type: none"> – Keeping familiar tasks – Remembering people's names better – Keeping brain active – Enjoying life more – Maintaining good relationships with family members, friends, and others – Minimizing frustration – Dealing with potential financial concerns – Driving safety • Part B: Guidelines for family members <ul style="list-style-type: none"> – Behavior change observations – Improving communication – Ways of encouraging your family member with MCI – Minimizing frustration

Topic Handouts	
	<ul style="list-style-type: none">– Handling potential driving problems– Preparing to deal with potential financial concerns– Making appropriate decisions for an adult family member with memory problems– Enjoying life more
Session VI: Finding Available Local and National Resources	
	<ul style="list-style-type: none">• Diagnosis and treatment• Prescription medication assistance resources, support group resources• Elder attorney assistance• Transportation• Other local resources• National resources

Table 3

What Couples Want In Intervention: Content Recommendations by Focus Group.

<p>Self-Management:</p> <ul style="list-style-type: none"> • Tips for self-management of medications, preparing a weekly medications box, or folding laundry: <i>PwMCI</i> • Add strategies for taking verbal or phone message: <i>PwMCI</i> • Present self-care content--self-administering medication and simple meal preparation (e.g., sandwich-making) or household management content (e.g., setting the table): <i>Spouse</i>
<p>Communication Skills--Ways to ...</p> <ul style="list-style-type: none"> • Tell spouse not to over-protect, not to take away work too soon: <i>PwMCI</i> • Tell spouse to allow PwMCI to do as much independently as possible for as long as possible: <i>PwMCI</i> • Ask for help, because they recognized that they frequently were unable to remember why and for what they needed help: <i>PwMCI</i> • Tell close family members or friends about their PwMCI's memory problem: <i>Spouse, Couple</i> • Help family members understand PwMCI's cognitive condition: <i>Spouse</i> • Improve communication among PwMCI and other close family members and friends: <i>Spouse</i> • Help family members and friends understand the need for planned, rather than impromptu visits: <i>Spouse</i> • Help PwMCI understand and avoid dangerous tasks, e.g., using an electric saw: <i>Spouse</i> • Respect PwMCI's self-selected activities while avoiding potential harm: <i>Couple</i> • Talk with children who refuse to discuss PwMCI's memory problems: <i>Couple</i>
<p>Technology Needs</p> <ul style="list-style-type: none"> • The need of information and training on technology-assisted devices such as simplicity of use, visible key size, screen light/dark contrast, and size of viewing frame: <i>PwMCI</i> • Discuss Global Positioning Satellite (GPS) technology to help find their way around while driving and mobile phones to easily contact persons as needed: <i>PwMCI</i> • Discuss importance of GPS technology to help PwMCI to find their way around and minimize arguments while driving: <i>Spouse</i> • Discuss usefulness of mobile phones to help contact each other easily and give sense of freedom during shopping: <i>Spouse</i>
<p>Emotions Management</p> <ul style="list-style-type: none"> • Have depression as a main session, because it is a common issue for PwMCI: <i>Spouse</i> • Emphasize ways to manage PwMCI's repeated questioning behavior and emotional distress: <i>Spouse</i> • Developing manageable strategies to organize things in order to help PwMCI do things independently such as placing personal items, small kitchen items, and house tools in the right place to minimize misplaced items: <i>Spouse</i> • The need for skill in managing PwMCI's emotional response such as being depressed, angry: <i>Couple</i>
<p>Program Implementation</p> <ul style="list-style-type: none"> • The length of the program, 6 sessions over three months, and the length of each session (60 to 90 minutes) is acceptable: <i>PwMCI, Spouse, Couple</i> • Biweekly meeting schedule can be difficult for working spouse who does not have regular working schedule: <i>Couple</i> • A flexible schedule was good for them: <i>PwMCI</i> • Either a convenient meeting place in a clinical conference room or individual's home was acceptable: <i>Spouse, Couple</i> • Offering such program in other cities around state would be good for them due to long distance driving: <i>Spouse</i> • A small support group program was also good for them: <i>Spouse, Couple</i>. • Holding the program either at the university clinical site or participant home was acceptable: <i>Couple</i> • The small group was helpful for them to share experience and find solutions: <i>Spouse, Couple</i>

<ul style="list-style-type: none">The weekday morning is the best time for them to attend the program, but be sure avoid rush hour: <i>Couple</i>
Recruitment Strategy <ul style="list-style-type: none">Physician referrals is the best strategy to invite people to attend the program: <i>PwMCI</i>The best strategies to invite people to attend the program include: physician referrals, advertisements on local newspapers, TV, or radio: <i>Spouse, Couple</i>
Reasons for Participating Study <ul style="list-style-type: none">To make a “contribution” for those with PwMCI and their family members: <i>PwMCI, Spouse, Couple</i>To gain knowledge about MCI and treatment-related information: <i>Spouse</i>To gain the knowledge and skills for living with MCI as well as living with PwMCI, because they had experienced significant life changes, affected by the gradual progress of memory problems: <i>Spouse</i>To gain knowledge and skills as much as they can, so they can deal with MCI: <i>Couple</i>