

## Satisfaction with a Family-focused Intervention for Mild Cognitive Impairment Dyads

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Abstract

**Purpose:** This paper describes satisfaction that persons with MCI (PwMCI) and their caregivers had with the Daily Enhancement of Meaningful Activity (DEMA) intervention.

**Methods:** This randomized controlled pilot study compared satisfaction (usefulness, ease of use, and acceptability) with DEMA ( $n = 17$  dyads) to an information support (IS) control group ( $n = 19$  dyads). Six bi-weekly sessions (2 in-person and 4 telephone) were delivered by trained nurses. Data analysis included descriptive statistics, independent-sample  $t$  tests, and content analysis.

**Findings:** PwMCI receiving DEMA rated their satisfaction significantly higher ( $p = .033$ ) than the control group; there was no difference in satisfaction between caregivers across groups. Qualitative interview data supported the usefulness, ease of use, and acceptability of DEMA for both PwMCI and caregivers.

**Conclusions:** Results documented PwMCI's satisfaction with DEMA as implemented by nurses to support PwMCI-caregiver dyads' engagement in meaningful activity. DEMA may need revision to increase satisfaction for caregivers.

**Clinical Relevance:** The DEMA intervention was evaluated as useful, easy to use, and acceptable to PwMCI and their caregivers based on positive mean ratings. The study findings provide preliminary support of the DEMA as a means to improve quality of life by helping supporting patients and caregivers engagement in meaningful activities and problem solving.

**Key Words:** Cognitive impairment, satisfaction, tailored intervention, dyad, meaningful activities, family caregivers

## Background

As the population ages, the prevalence of mild cognitive impairment (MCI) is increasing. The symptoms of MCI overlap significantly with those of early Alzheimer Disease (AD) and no disease-altering treatments for MCI or AD have been found. AD is the second most feared disease among American adults, and most Americans (62%) feel unprepared to care for a loved one diagnosed with AD (Foundation, 2011). Older adults with memory problems are at risk for physical functional decline, emotional distress, depressive symptoms, falls, and mortality (Panza et al., 2010; Wadley et al., 2009; Yaffe, Petersen, Lindquist, Kramer, & Miller, 2006).

Difficulties with memory are often associated with depressive symptoms in persons with MCI (PwMCI) and cause problems with financial or emergency management, dyadic communication conflict, decline in functional performance, decreased engagement in meaningful activities, and loss of sense of control (Bárrios et al., 2013; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008; Roland & Chappell, 2015). Engagement in meaningful activity is essential to the wellbeing of older adults with cognitive impairment in order to maintain a healthy active life style. Meaningful activities range from small daily rituals to the pursuit of one's overall purpose in life (Roland & Chappell, 2015).

Research findings regarding caregivers of PwMCI indicate they experience caregiving burden and negative effects on emotions, and they report needing services related to neurobehavioral symptom management (Paradise et al., 2015; Seeher, Low, Reppemund, & Brodaty, 2013). Caregiving for persons with MCI is challenging given the complexity of living with cognitive decline, the challenges of coping with non-curable cognitive impairment for long periods, and the fact that PwMCI have more awareness of their cognitive impairment and functional performance deficits than those with mild or late-stage dementia. Tailored educational interventions for caregivers designed to be delivered during that MCI window of opportunity

before progressing to dementia, are sorely needed (Roberts & Clare, 2013; Vogel et al., 2004). Such early prevention interventions may help PwMCI remain engaged or improve engagement in meaningful activities with support from their family caregivers. Additionally, caregivers may be better prepared for possible behavioral disturbances.

The Daily Engagement of Meaningful Activity (DEMA) intervention, a family-focused tailored intervention, was based on gerontological theory (Lawton, 1990), the Model of Human Occupation (Kielhofner, 2002), components of problem-solving therapy (Unützer et al., 2002), findings from two phenomenology studies of PwMCI and their caregivers, and a 3-phase DEMA intervention development study (Lu & Haase, 2009, 2011; Lu, Haase, & Farran, 2007; Lu, Haase, & Weaver, 2013). The purpose of this paper is to describe satisfaction with and acceptability of the DEMA intervention for PwMCI and their family caregivers compared to an attention control group. The value of DEMA as an intervention is contingent on evidence of patient and caregiver perceptions of usefulness, ease of use, acceptability, and overall satisfaction, prior to evaluating efficacy in a large study.

### **Design and Methods**

The study design was a two-group randomized, controlled pilot of DEMA in a sample of PwMCI-caregiver dyads. Study aims were related to feasibility, acceptability, and effect size of the DEMA intervention compared to an information support (IS) group (Lu, Bakas, Yang, Weaver, Austrom, & Haase, 2016). In this paper, we report quantitative and qualitative findings specifically related to our research questions: What are PwMCI and their caregivers' perceptions of satisfaction (usefulness, ease of use, acceptability) with the DEMA intervention compared to the IS attention control group? Institutional Review Board approval was received and all participants provided written informed consent prior to enrollment.

### **Setting, Sample, and Procedures**

**Setting.** All participants were recruited through the Indiana University School of Medicine's Alzheimer Disease Center. Participants were identified from the Alzheimer Disease Center registry, an IRB-approved registry maintained by the Indiana Alzheimer Disease Center. The registry includes information from volunteers who have consented to be contacted about available research.

**Sample.** Participants in the study were PwMCI patients who were able to read and speak English; had access to a telephone; were aged 60 or older, and met established MCI classification criteria (Winblad et al., 2004). PwMCI with significant neurologic diseases other than suspected incipient AD or with current major depression were excluded from the study. Caregivers were adults who were able to read and speak English, had primary responsibility for providing unpaid care to their partner, including monitoring safety and providing social support, and had a Six-item Screener score of 4 or above (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Potential participants who had a diagnosed bipolar disorder or untreated schizophrenia were excluded from the study. During a follow-up phone call prior to consent, eligible participants were fully informed about the study purpose, intervention procedures, and research evaluation procedures. Signed consent forms were returned by mail prior to the scheduled baseline assessment.

**Procedures.** Study recruitment was conducted by trained research staff and included two levels of eligibility screening. For Level 1, initial contact was made via recruitment packets mailed to 149 potential PwMCI-caregiver dyads, who were either in the Alzheimer Disease Research Registry or consented to be sent information after receiving a DEMA brochure during a clinic visit. The packet included the study brochure, opt-out call-in information, authorization

form for the release of health information for research, informed consent form, and a postage-paid return envelope. In Level 1 screening, 149 dyads were initially screened, 39 (26.2%) could not be contacted because they did not respond to the phone message, had a disconnected phone, or had moved out of state. Seventeen dyads (11.4%) were not eligible because the patient was deceased, there was no caregiver, or the patient or caregiver had other severe health problems. Fifty one dyads (34.23%) declined to undergo the second screening procedure for the following reasons: PwMCI or caregiver had a severe illness; conflict with caregivers' work schedules; denial about having MCI; driving distance; lack of physician support; and no reason give.

For Level 2 eligibility screening and consent, a follow-up phone call was made to the remaining 42 dyads. All dyads were fully informed about the study and procedures prior to consent. One dyad was found to be ineligible and one declined to participate due to a scheduling conflict. The remaining forty dyads (97.6%) signed individual consent forms and returned them by mail at least one week prior to their scheduled baseline data collection.

After receiving their assigned consent forms by mail, consenting dyads of PwMCI and their caregivers were contacted by phone to complete baseline data measures administered by the trained research staff. Immediately following completion of the baseline assessment, the statistician randomized participants ( $n = 40$  dyads) based on the MCI patient's Patient Health Questionnaire-9 Items (PHQ-9) score and stage of MCI (early or late). Participants were stratified by depression score (cut-point of 4) on the PHQ-9 and MCI stage (early vs. late) to randomize to the DEMA or IS attention control groups using a block-randomization approach with an independently generated allocation sequence. Stage of MCI was obtained from medical records. Early MCI was defined as individuals meeting clinical criteria for amnesic MCI, (i.e., scores between 0.5 and 1.5 SD below the mean of normal control on delayed paragraph recall

performance). Late MCI refers to self-reported memory impairment (i.e., memory has become worse) and performance on Delayed Recall Task scores of more than 1.5 SD below the mean (Aisen et al., 2010).

Some attrition occurred following randomization: One patient died, one caregiver became ill, one patient and caregiver separated, and one dyad withdrew due to a winter storm. Therefore, of 40 dyads, 36 completed the study, 17 in the DEMA group and 19 in the IS attention control group. Trained research staff conducted all telephone data collection. Sixteen dyads and one caregiver in the DEMA group completed a 3-month post-program data collection; one patient had progressed to AD and moved to a nursing home. In the IS attention control group, 18 dyads and one patient completed the 3-month post-program data collection; one caregiver in this group declined to participate in the data collection.

### **DEMA Intervention and IS Attention Control Group**

The dyads in both the DEMA and the IS attention control groups received the same contact modes (in-person and telephone) and attention time (6 bi-weekly individualized sessions—2 face-to-face and then 4 telephone sessions). The face-to-face sessions were held at the Indiana Alzheimer Disease Center Clinic.

**DEMA intervention.** The components of DEMA with results are reported elsewhere (Lu & Haase, 2011). The nurse-led DEMA intervention was designed for delivery in six biweekly 1-hour session (2 in-person session and then 4 telephone sessions), respectively, focusing on six self-management needs: (a) planning meaningful activity, (b) understanding MCI, (c) understanding the treatment of MCI, (d) understanding and dealing with negative emotional responses, (e) learning strategies for living with MCI and dealing with major concerns, and (f) finding available local and national resources. To tailor DEMA, patients and caregivers

separately completed the Dementia Deficit Scale to evaluate the PwMCI's level of awareness of his or her functional ability and the Canadian Occupational Performance Measure to assess the types and frequencies of daily meaningful activities and barriers to engaging in these activities.

Content for session 1 focused on introducing the PwMCI-caregiver dyad to the intervention and meaningful activity concepts, reviewing the PwMCI's history of meaningful activities, establishing a realistic and manageable meaningful activity plan. The PwMCI-caregiver dyad then set up goals and developed a plan for self-selected meaningful activities. During the 2 weeks between sessions, PwMCI-caregiver dyad worked on the agreed-upon goals and activities. In sessions 2-6, the first 30-40 minutes (Part I) focused on the specific meaningful activity that the dyad had planned during the previous session. DEMA used the principles of problem-solving therapy and, consistent with the overall goals of this intervention, provided autonomy support by helping patients identify and prioritize activities, classify needs and goals, generate manageable solutions, engage in self-selected activities with family support, and self-evaluate failure or success and renew problem-solving as needed.

The last 20-30 minutes (Part II) of sessions 2-6 was guided by the self-management tool kit and focused on one of the six counseling topics. The self-management tool kits is organized around the six self-management needs, PwMCI-caregiver dyads were encouraged to use the DEMA activity log at home, and the self-reported frequency and duration of activities were collected each session, within 10 days of completing the intervention and at three months post-program.

**Information support attention control group.** In the information support (IS) attention control group, during face-to-face meetings the PwMCI-caregivers received an overview of what would happen in the study and were given and reviewed an Alzheimer Association educational



brochure describing mild cognitive impairment. During the four biweekly follow-up phone calls, the dyads had the opportunity to talk to the intervener and ask questions directly related to the educational brochure.

### **Measures**

Satisfaction was evaluated in both groups using the Satisfaction with Meaningful Activity Program Scale (SMAPS). PwMCI and caregivers separately completed the measure through a telephone interview by a trained research assistant at three months post-intervention. The reason for assessing participants' perceptions on satisfaction with DEMA at three-month post intervention was to allow them to reflect on satisfaction with DEMA, the program implementation and continuation, and the long-term benefit of attending program. The SMAPS was adapted from the Caregiver Satisfaction Scale, which has high internal reliability (Bakas et al., 2009). Ten items are rated on the SMAPS using a 5-point Likert-type response scale ranging from 1 = *strongly disagree* to 5 = *strongly agree*. It took approximately five minutes to complete the measure. Participants in the DEMA group responded to the items about the educational materials in the Self-Management Tool Kit, and the IS attention control group rated the educational material in the Alzheimer's Association information brochure focused on MCI. Average SMAPS item scores were computed for each subscale (usefulness, ease of use, and acceptability) as well as for the total scale (satisfaction), with possible scores ranging from 1 to 5. Internal consistency reliability estimates using Cronbach's alpha for the usefulness and acceptability subscales and the total scale using the total sample of PwMCI ( $N = 33$ ) were acceptable (usefulness = 0.84, acceptability = 0.84; total satisfaction = 0.92); the alpha for the ease of use subscale was lower ( $r = .51$ ). For the caregivers, the Cronbach's alpha for all three subscales and the total satisfaction scale was acceptable (usefulness = 0.81, ease of use = 0.68, acceptability = 0.84, total satisfaction = 0.89).

After completing SMAPS, the DEMA group PwMCI and caregivers continued their phone call separately and privately and had audio-recorded open-ended telephone interviews with a trained evaluator who was not an intervener. An interview guide was used, and the primary data-generating item for the interview was: “Please tell me about your experiences being part of DEMA.” If needed, additional probes were used to assess usefulness, ease of use, and acceptability. These focused on: things that had helped participants maintain or increase daily meaningful activity; concerns about engaging in meaningful activity; things participants had most needed help with to remain engaged in meaningful activities; how participants had been treated by staff; the helpful or unhelpful things that others had said or done; what participants had learned from the program; what had been most helpful; any additional information regarding meaningful activity engagement that participants would like to have had or known more about; ways, if any, the intervener had been helpful; and family caregivers or other family members, if any, who became involved since enrollment in the program and how they had helped, if at all.

### **Data Analysis**

**Quantitative data.** All quantitative analyses were conducted using SAS 9.4 (SAS Institute Inc., Cary, North Carolina). The equivalences in demographic characteristics were identified between the DEMA and IS attention control groups by using two independent sample *t* tests for continuous variables as well as chi-square or Fisher’s exact test for categorical variables. These comparisons were examined separately for the PwMCI and their caregivers at baseline. The baseline age of PwMCIs was significantly different between two groups. Following evaluation of the SMAPS’ reliability, ANOVA model was performed to evaluate the satisfaction of interventions between two groups within PwMCI and their caregivers. When satisfaction was analyzed for PwMCI, the baseline age of PwMCI was included as a covariate. With 20 patients

(and caregivers) per group, our trial was powered to detect a standardized effect size  $d$  of 0.91 standard deviations with 80% power and a two-tailed alpha of 0.05 in baseline data collection. At three months post-program, with 16 patients in DEMA and 19 in the IS attention control group, our trial was powered to detect a standardized effect size  $d$  of 0.98 standard deviations with 80% power and a two-tailed alpha of 0.05. With 17 family caregivers in DEMA and 17 in the IS attention control group, our trial was powered to detect a standardized effect size  $d$  of 0.99 standard deviations with 80% power and a two-tailed alpha of 0.05. Three participants did not complete the SMAPS: one PwMCI in the DEMA group progressed to AD and moved to a nursing home; two caregivers in the IS attention control group withdrew from the study due to illness and separation from the PwMCI.

**Qualitative data.** Qualitative comments from PwMCI and caregivers in the DEMA group were content analyzed and categorized within three domains: usefulness, ease of use, and acceptability (Miles & Huberman, 1994). Microsoft Word was used for data management. Each telephone interview was audiotaped. After the audiotapes were professionally transcribed, the analysis team members, 2 researchers from various disciplines (Y.L. and J.E.), independently, listened to the taped interviews and read transcriptions for accuracy. Afterwards, a whole text analysis, open-coding method was used to identify significant statements, themes around usefulness, ease of use, and acceptability domains. The codes were developed from the major themes that emerged from the first phase of analysis, along with the original interview guides. The list of theme-generated codes was compared with the original interview guide and items that were not identified by the themes were added as codes. Subsequently, independent focused coding was carried out by the team and the team members discussed differences in the coding of significant statements until 100% agreement was reached. Where inconsistencies in the coding

occurred, the raters came to a consensus on discrepancies. Next, Y.L. and J.E. reviewed all coded transcripts to ensure that the final list of codes adequately reflected the data.

## Results

The 3-month satisfaction questionnaire was completed by 100% of the dyads (17 dyads in the DEMA group, 19 dyads in the IS attention control group).

**Sample Characteristics.** The sample of PwMCI was predominantly Caucasian (87.5%) and retired (87.5%), with a mean age of 74.2 years (DEMA group mean = 71.6,  $SD = 6.9$ ; IS attention group mean = 76.8,  $SD = 7.1$ ), mean education 16.5 years (DEMA group mean = 16.8,  $SD = 4.1$ ; IS attention control group mean = 16.2,  $SD = 3.9$ ), and more than half male (57.5%). Most patients had late MCI (55.0%), and 37.5% had a PHQ-9 score of five or more, suggesting depression. Caregivers had a mean age of 68.2 (DEMA group mean = 65.5,  $SD = 7.1$ ; IS attention control group mean = 70.8,  $SD = 11.9$ ) and mean education of 15.7 years (DEMA group mean = 15.4,  $SD = 3.2$ ; IS attention control group mean = 15.9,  $SD = 2.6$ ). Most caregivers were Caucasian (82.5%), female (75%), spouses (77.5%), and retired (65%); 30% had a PHQ-9 score of five or more. No significant differences between groups were detected, except that patients in the DEMA group were significantly ( $p=.023$ ) younger (mean age=71.6) than those in the IS attention control group (mean age 76.8).

**PwMCI satisfaction with the DEMA and IS attention control interventions.** PwMCI ratings for satisfaction with both DEMA and the IS attention control interventions were favorable, but the DEMA group indicated significantly ( $p <.05$ ) higher usefulness, ease of use, and total satisfaction than the IS attention control group (Table 1). Ratings of acceptability were high, but not significantly different by group. Specifically, the DEMA group had significantly higher scores for the usefulness items on how well the educational materials addressed their

problems and how well the nurse addressed things they wanted to know. The DEMA group also had significantly higher ratings than the IS attention control group for plans to use the educational material as a reference for the future.

[Insert Table 1 about here]

### **Caregiver satisfaction with the DEMA and the IS attention control interventions.**

Table 2 indicates that caregiver ratings for both the DEMA intervention and the IS attention control group were favorable, but not significantly different by group, although there was a trend toward higher acceptability in the DEMA group, particularly in reference to getting calls from the nurse.

[Insert Table 2]

### **Qualitative comments from the DEMA group**

**Usefulness of program.** Six main themes were found across PwMCI and caregiver comments: (a) *comprehensive beneficial program*; (b) *teamwork and communication*; (c) *prioritizing self-selected meaningful activities*; (d) *increasing awareness of cognitive changes*; (e) *increasing confidence and coping skill*; and (f) *learning of and using resources*. Examples of PwMCI and caregiver significant statements related to each theme are presented in the following paragraphs:

Both PwMCI and family caregivers perceived the DEMA program overall as *comprehensive and beneficial*: “It [DEMA program] covers a lot of areas in a person’s thinking and lifestyle ... the program is sort of an all-encompassing beneficial program. The program understands my problems... I would recommend this program to other persons with a memory problem.” (ID 40, male PwMCI); and, “It [DEMA program] has been good in more ways than I

can even tell you. ... It has helped him considerably ... it helps me...The memory is lot better and his depression is a lot better. He was having to do things, and write them down, and complete them, and [DEMA] makes him know that he can still do things and he had the ability.” (ID 56, female spouse caregiver). *Promoting teamwork and communication* were also perceived by both PwMCI and family caregivers: “... we can do the things that we are thinking are going to help us” (ID 10: female PwMCI) and “I call her every morning over phone, and I send her calendar and she is good at marking things on the calendar...I usually call her again around 4:00 p.m., then I call her again before she goes to bed to discuss the next day adventure (ID 10, daughter caregiver).

DEMA was also useful in specific ways. *Prioritizing and engaging in meaningful activities* were important aspects of DEMA: “It [the DEMA program] helps me to prioritize where I need to be focusing my energies” (ID 7, male PwMCI) and “It's important for him to continue to do some type of activity on a daily basis, and for myself also something that you can feel good about accomplishing, something that you reward yourself for getting it done” (ID 142, female spouse caregiver). DEMA also *increased awareness and management of cognitive changes*: “...it's hard for me to learn new things... I've learned some new tools on how to work around my memory problems” (ID 7, male PwMCI) and “...memory loss, the anger, and the depression that goes along with it, so being able to watch for those signs or knowing that it's going on I've learned that from the study” (ID 56, female spouse caregiver). *Increased confidence and coping skills* were also perceived by the dyads: “...What I noticed is at the end of the day when I'm tired, that everything is more difficult for me. I've had to learn to just not tackle anything big at the end of the day...Managing my stress level so I don't get overwhelmed and discouraged” (ID 7, female PwMCI) and “It [Self-management tool kit] was easy to do. It's

been so detailed and so good for me that I feel like I've got a handle on things now. When they get bad or get serious. I've got enough information ...” (ID 56, female spouse caregiver).

*Learning about and using resources* perceived as helpful by DEMA participants: “I’d say one thing to start with, you start right out with your green sheet [activity log] of your activities and when, how much time. You’re organized. That was helpful.” (ID 12, male PwMCI) and “Well, I think the fact that it’s there and that when things go south I at least know I can go to my resources and start digging from there. I think that’s a real huge.” (ID 142, female spouse caregiver)

**Ease of use of tools.** Both PwMCI and their caregivers reported the written self-management tool kits were easy to use and they would continue to use them in the future: “... I like the file, not on the computer.... I liked the green [self-management tool kit], just because you had it organized well. I think it’s very good..., and I read anything and everything that I think will help me...I mean I just look it up...if I need to refer to...” (ID 24, male PwMCI) and, “Whoever put this [Self-management Tool Kit] together did ... about the best job. I don't know anything else they could have done that would make this any better ... The fact that everything is just so detailed..., step by step and you don't have to try to figure it out (ID 56, female caregiver).

Both PwMCI and their family caregivers also indicated the activity log was easy to use and helpful: “It [Weekly Activity log] is important to write things down and monitor it. We're getting things done... because it helps to be doing it” (ID 73, female PwMCI) and “It was good to see that he did do well with setting the goals at the beginning when he would set the goals and when he would write those things down and do it that was helpful” (ID 24, female caregiver).

Caregivers raised a few concerns regarding the DEMA intervention. Specific qualitative comments were identified. "...The [DEMA] program was more focused on the patient than caregivers" (ID73, male caregiver). "We want more help as a caregiver" (ID 69, female caregiver) and "I would like to have received educational material [DEMA Self-management tool kit] for caregivers, but not the combined one" (ID 7, male caregiver).

**Acceptability.** Participants commented on frequency, delivery mode, and timing of sessions. Frequency was well accepted: "Every two weeks...it was very good, because I could bounce back to them how a week went and get feedback, so there was a lot of give and take, both ways" (ID 103, male PwMCI) and "Yes, I liked the spacing...spacing gives a person and particularly an older person for a chance to let it all sink in" (ID 40, male PwMCI). They also liked the delivery mode (i.e., first 2 in-person sessions at clinical setting, then 4 phone sessions), having face-to-face sessions for building a trusting relationship and follow-up sessions for convenience: "I think the way they had them set up was great. Giving at least first in-person session was essential for developing trust relationship at the beginning of program. "...It [the first session] gives you the face-to-face, it also gives you the opportunity to prepare and see what's ahead... may be a combination, by phone or on the computer, something like that would mean you didn't have to fight the traffic." (ID 3, male PwMCI). One [in-person session]..., because you get to see the person and know the person you're talking to, and I think seeing people helps you to see ... it does do something for you... (ID 21, female caregiver). Then the phone conversation after that is great because then it allows them to continue the program without having to come in... I think it's a good set up the way you've got it because most folks can make that first couple of sessions without too much to-do or get frustrated with the program



... because you have to try to figure out how to get there every week...They did a good job.”  
(ID 56, female caregiver).

Dyads discussed support groups as an alternative approach to delivery, but had mixed opinions. A key reason for lack of interest in support groups was uncertainty about what kind of people would be in the group: “I’d have to try it once and find out how it worked. It could be because a lot of people have a lot of different problems and you can say, oh, I’ve got that problem too or never thought of that. So sometimes it works and some don’t” (ID 10, female PwMCI) and “Yes, maybe if we’re farther advanced along. I don’t think right now I would participate in it but if things got worse I would” (ID 12, female caregiver). Some participants indicated interest in a follow-up support group, but were uncertain about frequency: “... I was thinking more like maybe some sort of meeting with other participants to talk about ...how we are doing. I’d say maybe every other month or every month” (ID 141, male caregiver).

### **Discussion**

In light of increasing emphasis on respecting the needs, values, and preferences of patients and/or their family caregivers (Epstein & Street, 2011), DEMA, as assessed by PwMCI and their family caregivers, was found to be useful, easy to use, and acceptable based on the positive mean ratings. In this study, satisfaction (usefulness, ease of use, acceptability) was measured using a scale that was adapted from the Caregiver Satisfaction Scale (Bakas et al., 2009). High internal consistency reliability for the total scale and for the usefulness and acceptability subscales was confirmed in our sample. The alpha for the caregiver ease of use subscale was lower. The sample size was too small to produce sufficiently precise internal consistency reliability estimates and fully evaluate psychometric properties of SMAPS in this pilot study (Charter, 2003).

The Ease of Use subscale ratings for PwMCI satisfaction were positive for both the DEMA intervention and the IS attention controls. Although overall satisfaction ratings were positive for both groups, DEMA ratings were significantly higher for PwMCI, which is encouraging. Similar to findings of a systematic literature review of stroke studies that analyze the evidence on the impact of family caregiver and dyad interventions on stroke survivor and caregiver outcomes (Bakas et al., 2014), results clearly indicate that the DEMA program was preferred by PwMCI, although the IS attention group also showed some level of benefit. On average, PwMCI in the DEMA group rated usefulness, ease of use, and acceptability, as well as their overall satisfaction, as high.

Although the caregiver ratings trended higher in the DEMA intervention versus the IS attention control for acceptability, the groups were not significantly different on any of the subscales. The DEMA intervention was tailored on the basis of MCI patient needs and caregiver's availability, teamwork with PwMCI, and structured progression of the patient's engagement. With an emphasis on patient confidence, DEMA caregivers may have sensed greater obligation to learn how to include and support the PwMCI's engagement, as opposed to focusing on the caregivers' personal engagement in meaningful activities. Similarly, previous studies have shown that caregivers had mixed perceptions regarding the benefits of engagement in activity together (McIlvane et al., 2008; Roland & Chappell, 2015). For example, a caregiver might feel pleasure and fulfillment engaging in an activity with their loved one as a way to recall memories of past times. On the other hand, the caregiver might experience stress associated with planning an activity, scheduling, and arranging for transportation or safety for the PwMCI.

Based on qualitative findings comparing DEMA PwMCI and caregivers, the caregivers expressed greater awareness and confidence in their role to support skill acquisition and

engagement, as well as improved abilities to communicate with PwMCI, to cope, and to problem-solve. By design, the IS attention control group was focused on social conversation and providing a “listening ear” for the participants rather than focusing on assessing needs, preferences, and strengths of the PwMCI. Therefore, unlike the DEMA group, the family caregivers in the IS attention control might have had more social conversation and perceived more understanding and acceptance from the “listening ear.” The specific qualitative statements indicated that caregivers would have preferred to receive more help to address problems related to dealing with a loved one with memory problems and having their own educational handbook to address their specific needs as a caregiver. These findings suggest we could modify DEMA in a future study to: 1) provide only the first session in person followed by five telephone sessions for establishing personal connection; 2) have joint sessions in the 3<sup>rd</sup> and 4<sup>th</sup> sessions focused on the meaningful activity engagement evaluation and plan, and then separate sessions to individually address the dyad’s needs and concerns.

Patient engagement and mastery were not emphasized in the attention control sessions, leaving room for caregivers to perceive and actually receive increased attention. The lack of session structure specific to the caregiver may have contributed to caregivers experiencing an elevated sense of individual (self) versus shared (dyad) efficacy to better connect with others, but it did not lead to greater satisfaction specific to their needs, and it may explain the lack of satisfaction differences between the DEMA and IS attention control groups.

In the qualitative interviews, PwMCI were able to explore their perceptions concerning experiences with the program and specify and comment on program usefulness. Caregivers were more able to provide reflective detail, articulate program benefits for themselves personally and report observed benefits for their loved one with MCI. Consistent with our previous study (Lu,

LU & Haase, 2011), the richness of the qualitative data provided insights and a better understanding of the actual experiences of the dyad enrolled in the DEMA group. The qualitative interviews clearly supported the three domains of satisfaction with DEMA program, and key quotes provided insight into the value of DEMA program. Many of the quotes reflect items in the Satisfaction Scale, providing support for the scale's validity.

Moreover, PwMCI and caregiver participants identified benefits associated with program design and implementation, including the dyad-focused intervention versus separate sessions and the highly valued toolkits. They also liked the number, timeframe, and mode of intervention delivery: two face-to-face and four telephone sessions, and the one-hour session length with a predictable agenda. Though both PwMCI and caregivers voiced interest in attending a support group specifically designed to meet information and support needs associated with experiencing or caring for a person with mild cognitive impairment, they also indicated uncertainty about their ability to attend and its value. The disadvantages of support group interventions, such as attrition, cost, and feasibility were discussed in a systematic literature review paper (Bakas et al., 2014).

Family caregivers often ignore their own healthcare needs and are commonly neglected by healthcare professionals in practice settings as MCI progresses (Ryan et al., 2010; Seeher et al., 2013). Because self-care is not usually a priority of family caregivers, they may need encouragement from healthcare providers to attend to their personal health needs (Ryan et al., 2010). Future study designs should be tailored to incorporate caregiver self-management tools specific to awareness of emotional distress, personal stress management, and self-care into the PwMCI-focused interventions (Andrieu, Coley, Lovestone, Aisen, & Vellas, 2015; Bakas et al., 2014). Developing interventions that include at least one separate time within sessions to address individual concerns and needs of living with or taking care of persons with cognitive impairment

has also been recommended by family caregivers (McIlvane et al., 2008; Ryan et al., 2010). Telephone interventions are less costly than in-person sessions (Lu, Bakas, & Haase, 2013), and having at least one in-person session for developing a trust relationship was strongly recommended by the both PwMCI and their family caregivers.

**Limitations.** This study had several limitations. First, the study had a small and homogeneous sample, which limits generalizability of the findings to more highly educated PwMCI who are predominantly Caucasian and to more highly educated family caregivers of PwMCI who are predominantly female, spouses, and Caucasian. Further research is recommended that includes a more diverse sample. Second, the qualitative data from PwMCI may be somewhat limited due to language decline related to the stage of MCI. We recommend that qualitative data collection regarding what was learned from the program and compliance should be collected two weeks post-program and three months post-program in future studies, while considering MCI progress relative to cognitive function.

### **Conclusion and Implications**

The DEMA intervention was evaluated as useful, easy to use, and acceptable to PwMCI and their caregivers based on positive mean ratings. The DEMA intervention was rated as being more useful and easy to use than the IS attention control group for PwMCI; however, the groups were similar with respect to acceptability. For caregivers, the DEMA and IS attention control groups were not different for usefulness, ease of use, or acceptability. Ways to improve DEMA for caregivers was discussed, and the high satisfaction ratings for the IS attention control group are beneficial in relation to our ability to retain participants in the IS attention control condition in a future study. A larger randomized control trial is needed to further evaluate DEMA efficacy. Considering that over the next 20 years 3 million baby boomers, who are more experienced in

using technology than previous generations (Clolby & Ortman, 2014), will reach retirement age each year, opportunity exists to explore use of meaningful activity interventions such as DEMA, which are delivered through technological options such as Skype and electronic activity monitoring and can be adapted for assisted living settings and delivered by occupational therapists, social workers, activity directors.

**Clinical Resources:**

- American Alzheimer's Association: <http://www.alz.org>
- Alzheimer's and Dementia Caregiver Center: <http://www.alz.org/care/>
- Health in Aging: <http://www.healthinaging.org>
- National Institute on Aging, Alzheimer's Disease Education and Referral Center: <https://www.nia.nih.gov/alzheimers>

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Table 1. Comparison of PwMCI Satisfaction (Usefulness, Ease of Use, and Acceptability) in DEMA and the IS Attention Control Groups

Item	DEMA Mean (SE) <sup>a</sup>	IS Attention control N = 19 Mean (SE) <sup>a</sup>	df	t	p-value
Usefulness Subscale	4.1 (0.2)	3.6 (0.1)	32	2.4	0.025*
The educational material addressed the problems I was having as a person with mild cognitive impairment	4.1 (0.2)	3.3 (0.2)	32	2.7	0.010*
The nurse addressed things I wanted to know.	4.3 (0.2)	3.6 (0.2)	32	2.5	0.018*
The educational material worked well for me.	3.9 (0.2)	3.7 (0.2)	32	0.7	0.518
The calls from the nurse helped me.	4.1 (0.2)	3.7 (0.2)	32	1.5	0.147
Ease of use subscale	4.1 (0.1)	3.7 (0.1)	32	2.2	0.038*
The educational material was easy to use.	4.2 (0.2)	3.8 (0.2)	32	1.7	0.102
I plan to use the educational material as a reference for the future.	4.0 (0.2)	3.2 (0.2)	32	2.4	0.021*
The calls from the nurse every other week were convenient.	4.1 (0.2)	4.1 (0.2)	32	0.2	0.830
Acceptability subscale	4.2 (0.2)	3.8 (0.2)	32	1.8	0.087
I liked the educational material.	4.2 (0.2)	3.7 (0.2)	32	1.8	0.087
I liked getting calls from the nurse	4.3 (0.2)	3.9 (0.2)	32	1.4	0.177
I would recommend program to other persons with memory problem.	4.3 (0.2)	3.9 (0.2)	32	1.4	0.180
Total Satisfaction Scale	4.1 (0.1)	3.7 (0.1)	32	2.2	0.033*

Note: Values based on 5-point Likert Scale: 5 = *strongly agree*; 4 = *have some agreement*, 3 = *no opinion*, 2 = *some disagreement*, 1 = *don't agree*. Educational Material: Self-Management tool-kits for the DEMA group vs. MCI-related educational pamphlet for the IS attention control. *df* = degree freedom.

a. Least square means and SE estimated from model were provided here. \*  $p < .05$

Table 2. Comparison of Caregiver Satisfaction (Usefulness, Ease of Use, and Acceptability) in DEMA and the IS Attention Control groups

Item	DEMA Mean (SE) <sup>a</sup>	IS Attention control  N = 17 Mean (SE) <sup>a</sup>	df	t	p-value
Usefulness Subscale	3.9 (0.2)	3.7 (0.2)	32	0.7	0.501
The educational material addressed the problems I was having as a primary care partner to a PwMCI	3.6 (0.2)	3.7 (0.2)	32	0.4	0.724
The nurse addressed things I wanted to know.	4.2 (0.3)	3.7 (0.3)	32	1.3	0.193
The educational material worked well for me.	3.9 (0.2)	3.7 (0.2)	32	1.0	0.346
The calls from the nurse helped me.	3.8 (0.2)	3.7 (0.2)	32	0.3	0.734
Ease of use subscale	4.0 (0.2)	4.0 (0.2)	32	0.1	0.933
The educational material was easy to use.	4.2 (0.20)	4.1 (0.2)	32	0.4	0.691
I plan to use the educational material as a reference for the future.	3.6 (0.3)	3.6 (0.3)	32	0.1	0.885
The calls from the nurse every other week were convenient.	4.3 (0.1)	4.3 (0.1)	32	0	> 0.999
Acceptability subscale	4.2 (0.2)	3.7 (0.2)	32	1.6	0.121
I liked the educational material.	4.1 (0.2)	3.6 (0.2)	32	1.5	0.146
I liked getting calls from the nurse	4.4 (0.2)	3.8 (0.2)	32	1.9	0.061
I would recommend program to other persons with memory problem.	4.1 (0.3)	3.8 (0.3)	32	0.8	0.413
Total Satisfaction Scale	4.0 (0.2)	3.8 (0.2)	32	0.9	0.362

Note: Values based on 5-point Likert Scale: 5 = *strongly agree*; 4 = *have some agreement*, 3 = *no opinion*, 2 = *some disagreement*, 1 = *don't agree*. Educational Material: Self-Management tool-kits for the DEMA group vs. MCI-related educational pamphlet for the IS attention control. df = degree freedom

a. Least square means and SE estimated from model were provided here; two caregivers missed questions due to health issues.