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A behavioral rehabilitation intervention for amnestic Mild Cognitive Impairment

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Abstract

Individuals with amnestic Mild Cognitive Impairment (MCI) currently have few treatment options for combating their memory loss. The Memory Support System (MSS) is a calendar and organization system with accompanying 6-week curriculum designed for individuals with progressive memory impairment. Ability to learn the MSS and its utility were assessed in 20 participants. Participants were significantly more likely to successfully use the calendar system after training. Ninety-five percent were compliant with the MSS at training completion, and 89% continued to be compliant at follow-up. Outcome measures revealed a medium effect size for improvement in functional ability. Subjects further reported improved independence, self-confidence, and mood. This initial examination of the MSS suggests that with appropriate training, individuals with amnestic MCI can and will use a memory notebook system to help compensate for memory loss. These results are encouraging that the MSS may help with the symptoms of memory decline in MCI.

Keywords

mild cognitive impairment; cognitive rehabilitation; memory loss; functional ability; behavioral interventions; memory notebook

Introduction

Amnestic Mild Cognitive Impairment (MCI) is the strongest identified risk factor for Alzheimer's disease (AD).¹ Interventions which help sustain functioning in MCI may delay progression to clinical AD. Frequently, the memory problems experienced by individuals with MCI negatively impact their lives, including mood, relationships, treatment compliance, and eventual independent living status. To date, interventions aimed at extending functional capacity in MCI have been pharmacologic in nature. While these medications may produce delays in progression of cognitive difficulties, individuals with MCI are also interested in additional activities they can do to manage their memory loss.

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Cognitive rehabilitation approaches that enhance functional independence in traumatic brain injury (TBI) may be applicable to MCI. Clinical practice guidelines in TBI include evidence based memory rehabilitation techniques that improve cognition and functional ability.² Memory rehabilitation can take two forms: 1) “memory building” techniques in which the goal is to regain memory function through repetitive training paradigms or 2) “memory compensation” techniques focused on using external aids to help adjust to memory loss. Memory notebooks are a form of memory compensation with validated efficacy in TBI patients.^{3, 4}

Research into memory rehabilitation in AD has primarily focused on memory building techniques with mixed results of effectiveness.⁵ The limited exploration of *memory compensation* aids in AD has focused on notebooks and calendars as a way of orienting significantly impaired individuals to date, basic schedules, and personal information with some success.⁶ A recent rehabilitation approach using both memory building and compensation techniques demonstrated that individuals with early AD showed improvements in orientation (from the use of the calendar), face-name associations, processing speed, and specifically trained functional ability.⁷ No published research exists to our knowledge using compensatory rehabilitation techniques with MCI patients.

Method

Study Participants

Twenty-four consecutive MCI patients and their program partners were recruited from the Mayo Alzheimer's Disease Research Center and through clinical referrals from Neurology/ Neuropsychology at the Mayo Clinic in Rochester, Minnesota from June 2005 to February 2007. This was a pilot study meant to examine the feasibility of teaching individuals with MCI to use a memory compensation system. Similarly, outcome measures were included in the pilot study to give a preliminary estimate of effect size for future power analysis. Use of a control group with randomization was deemed premature at this stage of this behavioral intervention project. Conduct of the study was approved by the Mayo Institution Review Board. Subjects met the following criteria:

Inclusion criteria:

- Diagnosed with amnesic MCI based on Mayo Criteria¹
- Had someone in regular contact with the participant willing to serve as program partner
- Dementia Rating Scale-2 (DRS-2)⁸ Total Score > 120

Exclusion criteria:

- Visual/hearing impairment or reading/writing disability sufficient to interfere with training

Assessment Schedule

At baseline and 8 weeks post-intervention, participants and their program partners completed two measures of functional ability, the Every Day Cognition (E-Cog)⁹ and Record of Independent Living (ROIL)¹⁰ as well as the Caregiver Burden scale (CB)¹¹. DRS-2 was given at baseline and repeated at 8-weeks post-intervention. Intervention sessions began 7-10 days after the initial assessment.

Training Paradigm

The Memory Support System (MSS) is a two-page per day calendar and note taking system small enough to fit in a man's breast pocket or woman's purse. The MSS includes three sections: 1) events that happen at a particular time, i.e., appointments, 2) events that can happen anytime, i.e., daily "to do" items, and 3) a journaling section, i.e., important events that happened that day. An example of the two page per day calendar can be seen in Appendix A. While sections 1 and 2 are often familiar from other calendar/day planner systems, the journaling section is unique to the MSS. This section may be thought of as similar to a diary, and is used for logging important things that happen during the day that are not appointments and not planned tasks. Examples may include an important phone call received, a relative's birthday, or news about family/friends the subject wants to remember.

A licensed occupational therapist specializing in cognitive rehabilitation and a Master's level psychologist served as MSS trainers. The MSS trainer provided each dyad with twelve, one-hour training sessions over six weeks. The first session began seven to ten days following the initial evaluation. Each person was provided with three sessions a week for two weeks, followed by two sessions a week for two weeks, and finally one day a week for two weeks, for a total of six weeks.

Intervention sessions provided orientation, modeling, practice use, and homework assignments. A typical agenda for a MSS training session included: 1) review of Intervention Plan/Questions and discussion, 2) review of homework and discussion, 3) learning phase appropriate instruction of MSS, and 4) assignment of next session's homework. MSS use was the sole rehabilitation intervention employed during training.

Learning phases—Three training stages from learning theory outlined by Sohlberg and Mateer for use in the TBI population were utilized ⁴: 1) an *acquisition phase* in which use of the MSS was learned, 2) an *application phase* in which a patient was taught to apply MSS use to his/her daily life, and 3) an *adaptation phase* in which a patient practiced incorporating the MSS into his/her daily life so as to make its use habitual.

Acquisition phase: The overall goal of the acquisition phase is to teach subjects the sections of the MSS and their intended use. This is attained by in-person instruction from the MSS trainer. Examples of items that should be written in each of the three MSS sections are either elicited from the subject or provided. For example, the MSS trainer often utilizes the time and date of the current training session to demonstrate the use of the appointment section of the MSS. Information relevant to the subject is used whenever possible, but hypothetical information can be used to demonstrate sections if needed.

Several other principles are taught during the initial MSS training. As subjects are thought to employ intact procedural or "habit" memory to learn and use the MSS, subjects are informed that they should carry the MSS with them at all times. Subjects work with the trainer to establish a method of knowing whether a task was completed or not, usually by placing an "x" or a checkmark next to the item in the appointment or "to do" sections. A schedule of at least three times during the day in which they will refer to their calendar is also established. We encourage linking taking the MSS out for review with established day-time routines such as meals and waking/bedtime.

It is also crucial during this learning phase that the MSS trainer assess any other calendar/note taking systems already in use by the subject. This most often is a combination of a month-view wall calendar in which the subject writes appointments, and multiple sticky notes and papers throughout the home, purse, or pockets with information the subject hopes to remember. These confusing systems are inevitably not working for the subject. The MSS trainer must work to

eliminate the use of any other calendars/note taking systems to avoid confusing and continued use of inefficient systems. This is usually done by having the subject bring the calendar/note system to the session, explaining how the MSS system will be more efficient in most cases, incorporating what they like about their own system into the MSS where possible, and, finally, disposing of the old calendar in preparation for the application phase.

Application phase: Once the sections and basic use of the MSS is established, the next goal is to apply its use in the individual's life. While hypothetical information may have been used as necessary in the acquisition phase, real life events important to the subject are now entered into each of the MSS sections and monitored for completion. Hence, on the surface, the training sessions have a “meeting over coffee” feel to them in which subjects discuss what they did the day before and their upcoming plans. The MSS trainer uses this information to practice MSS use with the subject. Subjects and program partners usually find sessions enjoyable for this reason.

Adaptation phase: After the subject is taught how to apply the MSS to their daily activities, the final training period focuses on adapting the MSS into the subject's daily routine, with the goal of making it a habit. This is attained by encouraging the subject to continue writing everything in the calendar on his/her own, and by the MSS therapist providing reminders to write down any events mentioned but not spontaneously placed in the MSS. Any questions about MSS use or areas of continued difficulty for the subject are addressed during this phase.

Intervention Plan/Questions—This set of questions was constructed to help the subjects learn each training phase (see Appendix B). These questions cover the topics to be learned in each phase of training. For example, the use of the date feature in the calendar progresses from asking where the date is located in the MSS (acquisition phase) to asking specifically what date it is today or last weekend (application phase), to the subject's spontaneous referral to the MSS for the date (adaptation phase). The MSS trainer initially models the administration of these Intervention Plan/Questions in session, training the subject and program partner in the use of cuing and the appropriate responses to questions. It is essential to the individual with MCI's learning of the MSS that the program partner practice the acquisition, application, and adaptation phases with the patient between sessions. To ensure this, the program partner is trained by the MSS therapist to ask the Intervention Plan/Questions that apply to the learning stage the patient was in twice a day as homework. The program partner was involved in this fashion so that the MCI subject received maximum training on the MSS while not overwhelming him/her with multiple daily therapy appointments. Subjects progress to the next training phase after demonstrating 100% accuracy on the Intervention Plan/Questions in a stage for five consecutive days. Program partners are taught how to cue and support the subject in the use of the MSS. Partners do not write in the subject's notebook, and care is taken through discussion with the trainer to ensure the subject is the one responsible for the MSS completion and not the program partner.

Homework—In addition to asking the Intervention Plan/Questions, homework is routinely given at the end of session to focus on the practice of a MSS skill. Assignment of homework always becomes practice of the “to do” section in addition to whatever other skill is being practiced. Examples of homework may include transferring information from a wall calendar into the MSS (requiring practice of the appointment section), writing down medications and checking them off (practice of the appointment or “to do” section), or calling a grandchild and journaling about the conversation (practice of the journaling section).

Compliance Assessment

At the end of the initial assessment meeting, participants received the MSS and were instructed to “begin using the calendar to help with your memory.” Spontaneous use of the MSS was then assessed at the first training session seven to ten days later to serve as the baseline for compliance. The compliance assessment was then repeated at training end and 8 week follow up. The MSS instructor examined MSS compliance for two separate days randomly selected from the week prior to the appointment. Random days were selected to offset the possibility of a participant “preparing” the calendar for their visit. Compliance was based upon four criteria for a maximum of 10 points:

1. The subject brought the MSS to the appointment (1 point)
2. The subject had at least one entry for today's date (1 point).
3. The subject had two entries over the two days for things that happened at a particular time (maximum 2 points).
4. The subject had two entries over the two days for things that did not need to happen at a particular time (maximum 2 points)
5. There were at least two entries for each of the two days in the journaling section (maximum 4 points).

Compliance was defined as a score of seven or greater on the Compliance Assessment.

Data Analysis/Handling

Statistical Package for the Social Sciences (SPSS) software was used in data analyses. Changes in compliance, functional ability, and program partner burden were assessed utilizing pair-wise t-test comparisons. Change in the percentage of participants determined “compliant” with the MSS were also analyzed utilizing a McNemar test.

Results

Twenty of the 24 subjects recruited completed training. The 20 individuals had a mean age of 78.2 ($SD = 5.8$; range 64-88), were college educated ($M = 15.2$, $SD = 2.5$; range 12 - 20), 70% male, and Caucasian. Program partners were most often a spouse (80%), but were also adult children (15%) or friends (5%). The four individuals who did not complete training were all females. No other significant differences were noted among demographics or baseline performances between those completing and not completing training.

Participants were significantly more likely to be compliant with the MSS after training ($M = 9.3$, $SD = 2.3$) than before ($M = 3.8$, $SD = 2.5$), $t(19) = -7.5$, $p < .0001$. Compliance remained high at 8 week follow up ($M = 8.7$, $SD = 2.7$). The percentage of individuals compliant at each assessment point is presented in Figure 1 (McNemar test $p < .001$).

Subjects not completing the training tended to have lower initial compliance. Two had compliance scores of zero, one had a compliance score of one. The remaining subject who did not complete training was compliant at baseline (compliance score of 8).

DRS-2 remained stable across the duration of the study. No significant differences were found from baseline to follow up on the ROIL or CB (see Table 1).

The E-Cog was given to the last 10 dyads pre and post intervention. While baseline ($M = 21.3$, $SD = 7.9$) and follow-up ($M = 17.0$, $SD = 7.7$) were not significantly different on the E-Cog for this small sample size [$t(9) = 1.9$, $p = .084$], there was a medium effect size for improvement in memory related activities of daily living ($d = .55$). Forty percent of individuals were taking

an acetylcholinesterase (ACh) inhibitor. Use of an ACh inhibitor was not related to MSS compliance or to performance on the E-Cog.

Discussion

We have created a curriculum and a calendar for individuals with amnesic MCI using strategies with proven effectiveness in TBI patients.⁴ Our work to date has been a feasibility project, i.e., Can individuals with MCI learn to use a calendar system, and will they use it? Our data suggest they can and do.

Many clinicians make the recommendation to their clients with amnesic MCI to take notes or keep a calendar. The current results, however, demonstrate that even after giving this instruction, a calendar to use, and the pressure of knowing someone would look at their calendar at the first session, only two of the original 24 subjects used the calendar effectively on their own. Four individuals lost all compliance points for not bringing the MSS as instructed to the first session, having either lost the MSS or not used it. No one was using it at home but had merely forgotten it. The remainder brought their notebooks, but they were unable to complete them appropriately. This suggests individuals with amnesic MCI need training to be able to successfully use a calendar/note taking system.

Only one subject who completed training was not compliant by the end of the intervention. That subject completed only the acquisition section, and never mastered the application section. She also was found to have limited insight into her memory difficulties. After the initial week of sessions, she was suspected of having progressed to Alzheimer's disease. This subject highlighted how careful screening for possible progression to dementia is important when a MCI subject is admitted to a study, as months or longer may have elapsed since they last saw their doctor regarding their cognitive condition. Two subjects who were compliant at the end of training failed to maintain compliance by the 8 week follow up. Both these subjects continued to carry the MSS with them, but were no longer effectively making entries in all sections.

In general, subjects appear to have the most difficulty learning and maintaining the journaling section. We suspect that this relates to 1) this section is less familiar to subjects than the standard appointment time and "to do" lists of traditional calendars/organizers, 2) as such, this is often the last section of the MSS to be acquired and utilized by the subjects, and 3) subjects with MCI often remember many significant events that have happened to them from day to day and comment that they do not need to write in a journaling section. We instruct the subjects in how the journaling section is in many ways like an "insurance policy." While we hope that they will not progress to the point where they need to write down important daily occurrences to remember them, we encourage them to learn and get in the habit of writing a journaling section in case they require it later.

Four of the 24 original subjects did not complete the intervention. These four subjects highlight how illnesses among this age group can impact ability to participate in a study spanning multiple visits and how subjects are more likely to participate when the intervention is provided close to where they live. It is worth noting, however, that almost all subjects contacted about taking part in this project were eager to participate despite the time commitment and sometimes driving long distances to attend.

Further exploration into characteristics of those not completing training revealed that two of the four individuals failed to bring their notebooks to the initial compliance session, one brought the MSS but had not used it, and the fourth was actually compliant with the MSS at the initial assessment. This suggests that having particularly low initial compliance (i.e., scores of zero or one) may impact ability/willingness to complete training. The ability of one discontinuing

subject to be compliance at the initial assessment suggests that further research will need to be done to determine what level of training, if any, is needed in these individuals. As previously noted, all four individuals who discontinued training were female, two of which had spouses for partners, and two of which were adult daughters. The two husbands were noted to have reported higher levels of caregiver burden compared to the rest of the sample [totals of 28 and 35 compared to the mean of 14.9 ($SD = 11.2$) in the remainder of the sample]. This small sample suggests that being female and having a highly stressed care partner may be additional risk factors for not completing training.

After the intervention, subjects routinely described the positive impact of the MSS on their lives (e.g., taking medications on their own again, returning to social activities, increased confidence, heightened sense of independence, lowered anxiety, and decreased sadness). However, improvements in functional ability proved difficult to quantify initially. Almost all existing measures of activities of daily living (ADLs) were developed for individuals with dementia. The ROIL used in this project is a good example. It quickly became apparent that individuals with MCI scored near the floor (i.e. were unimpaired) on this measure at baseline, making it impossible to assess improvement. This is perhaps expected since integrity of typical functional skills is required for a diagnosis of MCI. However, the E-Cog, a new measure designed to assess 'higher-order' instrumental ADLs in MCI, was useful in detecting a medium effect size of improved higher-order activities of daily living post-intervention.

Caregiver burden did not show significant changes after the intervention. This may be due to multiple factors. Most study partners denied symptoms of burden to begin with, as they did not view themselves as "caregivers" to the largely independent individual with MCI. Some individuals did experience notable decreases in reported burden. However, three program partners reported a significant increase in experienced burden. The program appeared to cause them to become more involved with their partner's memory on a daily basis, serving as a catalyst for increased awareness of the degree of memory loss. Increased burden from aiding the individual with MCI in learning the MSS should be a temporary issue, however, as the need for the program partner to practice the MSS with their loved one should decrease as the individual with MCI adapts the MSS into their daily routine. Obviously, a major goal of this work is to reduce caregiver burden. Thus, further research will be necessary to determine how issues such as prior time spent together, interaction and personality styles, and program partner awareness of memory deficit in their loved one all may impact caregiver response to MSS training.

Given the apparent success of this feasibility project, additional research is currently underway involving a randomized control group in which we have improved and expanded our outcome measures, including an appropriate index of activities of daily living and measures of mood, self-efficacy, quality of life, burden, and marital/life role satisfaction, and increased the duration of the follow-up period.

Conclusions

Behavioral interventions, such as cognitive rehabilitation, provide viable additional treatment strategies to ACh inhibitors in individuals with amnesic MCI. Our research suggests that individuals with amnesic MCI can and will use a memory notebook system to help compensate for their memory loss when they receive appropriate training. While gains in activities of daily living may be experienced in some individuals, this intervention is not expected to be a "fix" for MCI. Rather, the long term goals are that these individuals maintain functional independence for a longer period of time. Longer maintenance of independence is a tremendous benefit to those with MCI, their families, and the overwhelming healthcare burden faced worldwide in caring for those with dementia.

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Figure 1.
Percent of Subjects Compliant with the MSS at Assessment Points

Table 1

Non-Significant Outcome Measures

	Baseline	8-Week Follow-Up	P Value
DRS-2	129.4 (5.5)	128.3 (7.4)	.32
ADLs (ROIL)	7.2 (8.2)	6.6 (8.4)	.51
Caregiver Burden	14.9 (11.2)	13.8 (10.0)	.47

Note: DRS-2 = Dementia Rating Scale –2nd Edition, ADL = Activities of Daily Living, ROIL = Record of Independent Living