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The Development of a Manual-based Digital Memory Notebook Intervention with Case Study Illustrations

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Abstract

There is currently a need to identify feasible and effective interventions to help older individuals suffering from memory loss maintain functional independence and quality of life. To improve upon paper and pencil memory notebook interventions, the Digital Memory Notebook (DMN) application (app) was developed iteratively with persons with cognitive impairment. In this paper we detail a manual-based intervention for training use of the DMN app. A series of three case studies are described to illustrate the clinical process of the DMN intervention, the key components of the intervention and participants' perceptions of the intervention. The Reliable Change Index was applied to pre/post intervention scores that examined everyday memory lapses, daily functioning, coping self-efficacy, satisfaction with life, and quality of life with standardized measures. Following the intervention, two of three participants self-reported a clinically significant reduction in everyday memory lapses and improved everyday functioning. One participant reported clinically significant change in quality of life. All participants demonstrated clinically significant changes in their ability to cope with problems and build self-efficacy. Furthermore, all participants scored in the normative range post-intervention on the measure of satisfaction with life. Clinical observations and participant feedback were used for refinement of the DMN intervention (ClinicalTrials.gov NCT03453554).

Keywords

cognitive rehabilitation; technology; memory; mild cognitive impairment; brain injury

Introduction

Cognitive impairment can be caused by a number of diseases and conditions throughout the lifespan, including dementia, stroke, traumatic brain injury, and developmental disorders. Individuals with cognitive impairment can experience difficulties across varying domains, including learning and remembering new information, concentrating and making decisions. Cognitive impairment is associated with billions of dollars in health care costs and can lead

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to drastic changes in an individual's everyday functioning (Alzheimer's Association, 2018; Andrews et al., 2017). Common negative consequences of cognitive impairment include difficulties completing activities of daily living (e.g., meal preparation, managing finances, chore completion), decreased self-efficacy, mismanagement of chronic health conditions, lower quality of life, and social withdrawal (Farias et al., 2006; Wagster, King, Resnick & Rapp, 2012). Age is the primary risk factor for the development of mild cognitive impairment (MCI) and dementia, and the aging population of the United States is growing at an unprecedented rate (Centers for Disease Control and Prevention, 2016). Currently, there is an urgent need to provide feasible, efficacious and scalable interventions that will help individuals experiencing cognitive impairment maintain everyday independence and quality of life while also decreasing caregiver burden and health care costs.

Deficits in memory and executive functioning have most consistently been associated with difficulties initiating and completing everyday activities (e.g., Rabinowitz & Levin, 2014; Schmitter-Edgecombe, Parsey & Lamb, 2014). To support limitations that arise as a result of these cognitive changes, a wide range of evidence-based approaches to cognitive rehabilitation have been established. At a general level, these approaches to cognitive rehabilitation can be categorized as rehearsal-based strategies, internal compensatory strategies, and external compensatory aids. *Rehearsal* based strategies emphasize continuous repetition of information (Hampstead, Gillis, & Stringer, 2014). Conversely, *compensatory* strategies aim to alter how an individual learns, retains, and retrieves information (Hampstead et al., 2014). Training in compensatory strategies is often less-time consuming and more generalizable than rehearsal-based strategies. Internal compensatory strategies rely on mnemonic techniques to organize and associate new information with processes such as semantic elaboration and mental imagery. Internal compensatory approaches are resource demanding and cannot easily support the varied and large quantities of information that may need to be remembered on a daily basis. External compensatory approaches, on the other hand, utilize aids to organize and retrieve a diversity of information. In contrast to internal compensatory strategies, external aids decrease the burden on executive and memory processes.

External compensatory strategies, including memory notebooks, have become a practice standard for individuals with cognitive impairment due to traumatic brain injury (TBI) and stroke (Cicerone et al., 2011). Recent evidence also suggests that external compensatory strategies improve daily functioning in persons suffering from MCI (Greenaway, Duncan, & Smith, 2013; Schmitter-Edgecombe & Dyck, 2014; Troyer, Murphy, Anderson, Moscovitch, & Craik, 2008) and mild Alzheimer's disease (AD; Quittre, Olivier, & Salmon, 2005; Schmitter-Edgecombe, Howard, Pavawalla, Howell, & Rueda, 2008) as assessed by performance-based measures. Memory notebooks are especially advantageous external aids, as they can help support retrospective and prospective memory, both of which have been found to be important for supporting everyday functioning (Beaver & Schmitter-Edgecombe, 2017; Schmitter-Edgecombe, Woo & Greeley, 2009).

Traditional paper and pencil memory notebooks, however, have limitations. These include easy navigation to the current date for notebook entries, remembering to use the memory device, and organizing and retrieving specific information as information accumulates over time in the form of pages, notes, or bookmarks (Hampstead et al., 2014). Some of these limitations can be overcome by using a digital format. For instance, cueing and organization methods can be incorporated into digital notebooks to ensure that individuals enter information into the correct section (e.g., clear navigation to current date) and can easily locate information (e.g., search features). Digital formats can also manage more detailed and complex information over time compared to paper and pencil formats. In addition, as individuals begin to depend on external aids, creating a reliable system that is minimally susceptible to damage or information loss is important. Teaching an individual with memory impairment to effectively use a paper and pencil memory notebook is also time consuming (typically greater than 14 sessions; Schmitter-Edgecombe, Fahy, Whelan & Long, 1995; Schmitter-Edgecombe & Dyck; 2014) and involves assisting the individual with remembering to use the device. To engage individuals in the routine use of a memory notebook, externally directed assisted devices (i.e., external alarms) are typically used (Cicerone et al., 2011). However, individuals must set these separate external alarms and remember that the alarm is cueing memory notebook use. A further advantage of a digital format is the capability of including built-in training alarms to promote memory notebook use.

The Digital Memory Notebook (DMN) is an iOS application (app) on a tablet, with a keyboard attachment. The DMN app and accompanying intervention detailed in this paper were developed to decrease training time and improve previous interventions that have utilized paper and pencil memory notebooks as compensatory aids for individuals suffering from memory impairments. Previous iterations of a traditional memory notebook (Schmitter-Edgecombe et al., 2008; Schmitter-Edgecombe & Dyck, 2014), which included hourly logs to record daily activities, to-do lists, a goal setting page, a notes section, and a calendar, were used as the starting point for the development of the DMN app. To optimize the utility, usability, and functionality of the application for individuals with memory impairment, the design process was guided by cognitive rehabilitation principles and by design principles for creating mobile applications for older adults (Diaz-Bossini & Moreno, 2014). Furthermore, the DMN app was developed in collaboration with individuals with memory impairment through five rounds of participatory design and iterative feedback from individuals with MCI, traumatic brain injury (TBI) and care-partners (for DMN development details, see Dahmen, Minor, Cook, Vo, & Schmitter-Edgecombe, 2018; Raghunath, Dahmen, Brown, Cook & Schmitter-Edgecombe, in press). The final DMN app, contains four main components (Today/Home, Calendar, Profile, Notes) and a Help section. Each component includes guiding text and is easy to use. Furthermore, we have demonstrated that the DMN app is user-friendly despite individual differences in level of memory impairment, familiarity with scheduling tools and experience with technology (Raghunath et al., in press).

According to Sohlberg and Mateer (1989), providing a memory notebook to individuals with memory impairment is not sufficient to improve functioning. Building on prior work (Schmitter-Edgecombe, et al., 1995; Schmitter-Edgecombe et al., 2008; Schmitter-Edgecombe & Dyck, 2014; Sohlberg & Mateer, 1989), the DMN manual-based intervention was developed to provide individuals with training in how to use the DMN and incorporate it into their daily routine. The DMN training includes a client workbook and a clinician manual. The DMN intervention utilizes a structured interactive format, consisting of didactics, skills training, goal setting, problem-solving, and supportive bonding between the clinician and participant over a period of five to six sessions, each of which lasts approximately 90 – 120 minutes, and are completed within a one-month time frame. Flexibility is built into the number of sessions so that the clinician can individualize the pace of the intervention to fit the client's skill level, comfort with technology, and comprehension of the material. The approach utilizes a systematic learning method, first used by Sohlberg and Mateer (1989) for memory notebook training, which consists of four stages: anticipation, acquisition, application, and adaption (see Table 1). Incorporated throughout each of these stages is the creation of a routine to facilitate an overlearned habit of regular use of the DMN and to foster reliance on procedural memory processes. Furthermore, both the design of the DMN app, which was built iteratively based on user input, and the text-based cueing support errorless learning by promoting a high level of correct responding. Errorless learning methods have proven to be more effective than trial and error learning when working with individuals with cognitive impairment (e.g., MCI), especially when ability to monitor and detect one's own errors is compromized (Roberts et al., 2018).

In addition to the quality of training, the quality of training manuals has been shown to be a crucial component in facilitating use of new technology by older adults (Barnard, Bradley, Hodgson, & Lloyd, 2013). It is important that training manuals are not too complex and full of technical jargon (Barnard et al., 2013; Morrell & Park, 2000). Older adults may also struggle with lengthy procedures or instructions that can tax working memory (Mayhorn, Stronge, McLaughlin, & Rogers, 2004). With these factors in mind, the client workbook was designed to have clear and simple step-by-step instructions detailing how to use all of the features of the DMN. Images and screenshots of the DMN app pages with functions and buttons highlighted are included with the step-by-step instructions to further aid in and elucidate the learning process. The addition of images with gradual instructions may also assist in the conceptualization of the interface of the application for individuals who may have poor working memory and spatial abilities (Mayhorn et al., 2004). The workbook aims to stimulate learning through both verbal and visual modalities and is available for individuals to reference between in-person training sessions.

The current paper describes the clinical process of the DMN intervention, clients' perceptions of the intervention, and preliminary evaluation of the intervention through a series of case studies. The experiences of three individuals with cognitive limitations are described and used to help illustrate the importance of several components of the intervention. These individuals participated in pilot work to refine the DMN workbook and clinician training materials. We hypothesized that for each participant the intervention would lead to a reduction in everyday memory lapses, as well as improved everyday functioning, coping self-efficacy, quality of life and satisfaction with life.

Method

Participants

To increase the generalizability of the findings, the three Case study participants varied in age (39 – 72 years old), etiology of cognitive impairment (traumatic brain injury, history of concussion, Parkinson's disease), and experience with technology (minimal familiarity – daily technology use). All participants had insight into their memory difficulties and were requesting assistance to help improve their everyday functioning. None of the participants scored in the clinically depressed range (10–15) on the Geriatric Depression Scale – Short Form (Sheikh & Yesavage, 1986). All three participants reviewed the illustration of their case, were given the opportunity to request changes to their case, and provided written consent for their case to be included in this paper. Additional details about each participant are presented within each case study in the Results section. The study protocol was also reviewed and approved by the Washington State University Institutional Review Board.

Cognitive Assessment

The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, Tierney, Mohr, & Chase, 1998) was administered to document level of cognitive function for each Case study participant. The RBANS is a brief standardized cognitive screening tool used to assess neuropsychological functioning (Randolph, et al. 1998). A total standard score and percentile rank based on normative values for same-aged peers can be derived.

Outcome Measures

Functional Abilities—The Instrumental Activities of Daily Living – Compensation (IADL-C; Schmitter-Edgecombe, Parsey, & Lamb, 2014) scale is a 27-item measure of functional ability, where participants rate their ability to complete various IADLs on an 8-point Likert scale ranging from 1 ("independent, no aid") to 8 ("cannot complete this activity anymore"), with higher scores indicating greater difficulty with completing everyday tasks. The IADL-C has shown good internal consistency across subscales (Rasch reliability .80 to .93) and test-retest reliability (Spearman coefficient .91) and has demonstrated ability to discriminate individuals with MCI from healthy older adults (Schmitter-Edgecombe et al., 2014).

Everyday Memory—The Prospective and Retrospective Memory Questionnaire (PRMQ; Smith, Della Sala, Logie, & Maylor, 2000) is a measure of everyday memory difficulties an individual may experience. It consists of 16-items, each rated on a 5-point Likert scale, ranging from 5 ("very often") to 1 ("never"), with higher scores indicating greater self-reported difficulty with everyday memory. The total scale has good test-retest reliability (.89).

Coping Self-Efficacy—The 13-item Coping Self-Efficacy Scale (CSES; Chesney, Neilands, Chambers, Taylor, & Folkman, 2006) was originally developed as a 26-item measure (see Chesney et al., 2006 for the reliability of the full measure). Participants rate their ability to use skills to adapt to different problems in each item on an 11-point Likert scale that ranges from 0 ("cannot do at all") to 10 ("certain can do"). Higher scores indicate greater levels of coping self-efficacy.

Satisfaction with Life—The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen & Griffen 1985) was developed to assess life satisfaction and overall well-being. The scale consists of five questions assessing general life satisfaction, with each item rated on a 7-point Likert scale ranging from 1 (“extremely dissatisfied”) to 7 (“extremely satisfied”), with higher scores indicating greater satisfaction with life. The SWLS has demonstrated good test-retest reliability of .85. Studies (e.g., Pavot & Diener, 1993) have also demonstrated that the SWLS is sensitive enough to detect clinically significant change in life satisfaction following an intervention.

Quality of Life—The Quality of Life – Alzheimer’s Disease (QoL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999) measure was originally designed to assess quality of life (QoL) in individuals with Alzheimer’s disease but has been used to asses QoL in diverse populations, including non-demented older adults. It is a 13-item measure that has participants assess various domains of quality of life (e.g., physical health, energy, memory) on a 4-point Likert scale, ranging from 1 (“poor”) to 4 (“excellent”), with higher scores indicating better quality of life.

Procedure

The RBANS was administered by a trained examiner in a testing session prior to the start of the intervention to determine the cognitive status of each participant. Self-report measures assessing everyday functioning, everyday memory, coping self-efficacy, satisfaction with life, and quality of life were also administered. Participants then received manualized training in use of the DMN from a trained clinician. This training was developed to take place across the span of four weeks, with flexibility for training to occur across five *or* six sessions as needed by the participant. All training sessions were approximately two hours long and took place in the participant’s own homes, to promote the usability of the DMN in the participants’ everyday life. An in-home intervention also allowed for involvement and easier access to caregivers.

The systematic learning method (Sohlberg & Mateer, 1989) was utilized to promote adherence to using the DMN by structuring the intervention around each participant’s unique needs and motivating the participant to engage in the intervention with a sense of self-efficacy.

There are four stages of the systematic learning method that parallel the goals of the training sessions: anticipation, acquisition, application, and adaptation. Broadly, the *anticipation stage* involves an assessment of the client’s everyday memory difficulties and needs, in addition to providing psychoeducation and demonstrating the value of compensatory strategies. The *acquisition stage* aims to teach the use of the DMN app and initiate development of new behaviors. This is achieved by having the client begin to develop a routine around the DMN. During this stage, an hourly training alarm is activated for three to four days during waking hours to encourage consistent use of the DMN and development of an overlearned habit of looking at and writing in the DMN. The *application stage* consists of teaching the client how to determine when and where to utilize these newly developed skills. The clinician works with the client to determine how they can improve their time management and task completion success rate by using the DMN daily to-do list and advanced scheduling features. Lastly, the *adaptation stage* involves adapting the skills learned to more broadly support everyday functioning. The client learns how to expand the utility of the DMN to foster memory, well-being, and project completion, as well as create and implement long-term goals. More in-depth psychoeducation on brain health and longer-term goal setting is also provided to inform these processes and encourage the use of the notes and journaling sections in ways that will best promote the autonomy of the individual client. For more details about each of these sections, see Table 1. Throughout the intervention, the DMN design and the text-based cueing help to promote errorless learning, thereby leading to lower frustration and easier mastery of the DMN.

Analysis

To determine whether the intervention resulted in a reliable change in the outcome measures for each participant, we used the Reliable Change Index (RCI; Jacobson, Follete, & Revenstorf, 1984) with an alpha-level of .05. The RCI represents the amount of change an individual must exhibit on a measure from pre-test to post-test for the change to be considered clinically significant. First, Reliable Change (RC) scores were calculated for each measure to determine the statistical reliability of change. To compute RC, normative data for each outcome measure (mean score, standard deviation, test-retest reliability) were collected. When available, published normative data was used for these calculations. If unavailable, normative data were computed using local norms (see Tables 2, 3, 4). Using this normative data, the standard error of measurement (SE_M) for each measure was first computed. The SE_M was then used to determine the standard deviation of the errors of measurement of the difference scores (S_{DIFF}). The S_{DIFF} was then divided by the difference score for each participant (post-test score – pretest score) to determine the RC value. If the RC value was greater than or equal to ±1.96, the change in scores between pre-test and post-test were considered statistically reliable and not due to measurement error. To determine if the change was clinically significant, the S_{DIFF} for each measure was multiplied by 1.96 to determine the absolute value required for a difference score to be considered reliable. If the absolute difference score for the measure was greater than the computed RCI value, the change was considered clinically significant. Differences in scores needed to be both statistically and clinically significant to be considered reliable change.

Results

Case Study 1

General background—The first participant was a married, 69-year-old female. She completed 14 years of education, including vocational training. The participant was retired at the time of the intervention and previously worked in a public works position for 30 years. She was living with her husband and was the primary care partner for her mother-in-law. The participant self-reported experiencing gradual changes in memory, which began approximately three years prior to the intervention following a mild TBI. As a result of the TBI, she reported that significant difficulties with concentration negatively affected her ability to safely engage in activities such as driving for several months. She also reported several other medical conditions including an autoimmune condition, arthritis, mobility issues related to pain due to prior injuries, and vision and hearing difficulties.

Memory Concerns—Primary memory concerns endorsed at the beginning of the intervention included difficulties recalling information about past events and remembering to complete chores and keep appointments. She also endorsed difficulties with word finding, time management, organization, and initiation of activities. She reported experiencing guilt related to her cognitive difficulties because she often missed social engagements and had difficulties communicating with others. Additionally, she endorsed experiencing anxiety due to concerns of becoming dependent on her spouse to complete daily activities. Consistent with her self-reported difficulties, her RBANS sum of indexes (80) fell within the Borderline range (9th percentile).

Summary of Intervention Notes—During the course of the six sessions of intervention, the participant experienced difficulties understanding some aspects of the DMN functionality. For instance, in session 3, she had difficulty understanding the purpose of the to-do list and scheduling appointments with herself to complete daily tasks. She also reported feeling pressured to add a start and end time to her to-do list items because she perceived her household as unpredictable due to her caretaking responsibilities. With the support and facilitation of her husband, the tutorial was reintroduced in a way the participant could understand. The clinician also worked with the participant to routinely add the start/end time of a to-do list task after she completed the task (versus when scheduling the task). This adaptation enabled the participant to feel less overwhelmed and at the same time allowed her to track her activities and feel positive about her accomplishments. The participant also found it helpful at times to write down items on paper and then enter them into her DMN. One week the participant self-reported delaying her entries in the DMN. She indicated that this experience reinforced the utility of the DMN and her motivation to use it as she found that she had substantial difficulty answering questions about what she had done during that week because her tasks were not entered into the DMN. Primary uses of the DMN for this participant included recording information about shows and movies she watched, activities she needed to engage in to care for her mother-in-law, household chores, meals, social outings, church activities, and self-care activities.

Despite some initial difficulty learning to use aspects of the DMN, by the end of the DMN training sessions, the participant was making 3–5 detailed entries per day and reportedly checking the DMN each time she went into her living room. Post-test data was collected 9 weeks following completion of the intervention (i.e., about 3 months following pre-test). As seen in Table 2, in comparison to her pre-intervention scores, the participant self-reported a significant improvement in ability to complete IADLs and a significant decrease in everyday memory difficulties. She also endorsed significant improvement in her coping self-efficacy and satisfaction with life. Although not reaching the level of clinically significant reliable change, there was also a positive change in her score on the quality of life measure with her score now falling close to the normative mean. In support of these findings, at follow-up the participant described experiencing less stress and embarrassment with remembering information because she could depend on the DMN to facilitate her recall of information. The participant's spouse indicated that, following session three, he noticed a substantial difference in her stress level and ability to recall information when she did not use the DMN.

Case Study 2

General background—The second participant was a single, 39-year-old female. She achieved a high school diploma. At the time of the intervention, she was a stay-at-home mother with an infant son, with family living in the neighborhood and available to assist her with activities as needed. The participant suffered a severe traumatic brain injury (TBI) in her early twenties. She had a second medical event in her early thirties that exacerbated her cognitive difficulties and led to additional diagnoses, including major depressive disorder, post-traumatic stress disorder, and social anxiety disorder. These diagnoses coupled with the neurocognitive side effects of the TBI led to an inability to work since her mid-thirties.

Memory Concerns—The participant self-reported experiencing apathy, cognitive slowing, forgetfulness, distractibility, decreased cognitive acuity, and headaches. Her RBANS sum of indexes (71) fell at the 3rd percentile (Borderline range).

Summary of Intervention Notes—The participant began the five sessions of intervention with familiarity with digital scheduling tools, notes, and reminders, as assessed via scheduling tool use and technology comfort questionnaires (Raghunath et al., in press; Tam, Von San, Dyck & Schmitter-Edgecombe., 2017), and found it easy to transition to using the DMN. This participant reported that her initial learning curve was not related to technology, but rather in learning the best ways to record information and to incorporate the DMN into her routine. She found the training sessions helpful, but less tailored to individuals with more experience with technology. On the other hand, she described an appreciation for the simplicity of the DMN app, as it allowed her to focus on other aspects of the intervention (e.g., scheduling more efficiently, recording more information).

The participant reported that the DMN helped her organize her daily tasks and establish a routine, especially with her son (e.g., keeping track of feeding schedule). She also reported recording additional details of conversations in the hopes of mitigating the consequences of forgetting what someone had told her. It was also helpful for her to be able to easily go back through the DMN to see her progress throughout the day and add more information to the entries. She described enjoying the incorporation of self-care and brain health activities into the DMN intervention and indicated that she would have liked to spend more time on these components of the intervention.

Post-test data was collected from this participant approximately 7 weeks after completion of the intervention (i.e., approximately 3 months from pre-test). As seen in Table 3, the participant self-reported significant positive changes in her everyday functional abilities and memory difficulties as well as coping self-efficacy, satisfaction with life, and quality of life. These changes were supported by the participant's report at follow-up that the DMN contributed to the development of a routine and to increased confidence in her ability to initiate and complete activities. She described checking off activities to be a rewarding experience as she was able to complete something and get credit for it. This accompanied an improved sense of accomplishment, with the participant reporting "it is hard to ignore how many tasks I achieve in a day," which was particularly important as she experienced difficulties with low self-concept.

Case Study 3

General background—The third participant was a widowed, 72-year-old female. She achieved a high school diploma, and had previous occupations that included waitress, truck driver, and janitorial staff. The participant was retired at the time of the intervention. She lived alone in her home and received occasional visits from family members that did not live nearby. The participant was diagnosed with Parkinson's disease and had been experiencing gradual changes in her memory for approximately 4–5 years, with more notable changes within the 6 months prior to the intervention. The participant also reported several other medical conditions including arthritis in her hands, thyroid disease, visual difficulties, ringing in the ear, mobility issues related to prior injuries, and chronic pain.

Memory Concerns—Primary memory concerns endorsed by the participant included difficulties with remembering how to do familiar things, keeping appointments, and recalling information about past events. She also endorsed difficulties with word finding, time management, organization, and initiation of activities. Her RBANS sum of indexes (84) fell within the Low Average range of functioning (14%).

Summary of Intervention Notes—The participant had minimal experience with technology making it difficult for her to engage in her primary outlets for self-care, which included communicating with friends and family and using her sewing machine. Following six sessions of DMN training, the participant described becoming more comfortable with technology in general and more confident in her ability to use the DMN on a regular basis. She also became more efficient at typing the more she used the DMN, which she reported as exciting. Learning to use the DMN increased her self-efficacy in general and decreased the stress she experienced when attempting to write information when her tremoring increased (now she typed). She also found scheduling self-care activities and sewing projects into the DMN helpful to prevent overworking and unfinished tasks.

Post-testing occurred approximately 17 weeks following the end of the one-month DMN intervention (i.e., about 5 months following pre-testing). As seen in Table 4, the data showed that despite no reliable changes in reported functional abilities, memory, satisfaction with life, or quality of life, the participant self-reported significant changes in her coping self-efficacy. The change in coping self-efficacy was supported by the participant's statement that "I live by the DMN now … and it has made me a more reliable person". In particular, she reported that she had been able to attend doctor's appointments and take her medications more consistently. She also endorsed a decreased level of stress and an overall increased sense of accomplishment and confidence. Furthermore, the participant indicated that it was very helpful to look across the house at the DMN and see all the important reminders and information in one place without having to walk far due to her mobility issues. Although change was not detected in everyday memory difficulties, she reported that having this backup system for memory was very important to her. In terms of the intervention, she indicated that the intervention was fun and engaging, and challenged her appropriately. Additionally, although change in life satisfaction was not clinically significant, her scores improved, resulting in a post-intervention score nearly as high as the mean of the normative range. This change in satisfaction with life was supported by the participant's report that she felt the DMN made her feel more secure in her life, as well as more organized and efficient.

Discussion

Traditional paper and pencil memory notebooks have been utilized as external memory aids for individuals with cognitive impairment (Cicerone et al., 2011). However, paper and pencil memory notebooks have limitations, such as limited space, requirement to use extraneous strategies to orient to time and place to ensure recording of information on the appropriate day, and use of external assistive devices to remind individuals to use their memory notebooks. In response to these limitations, we developed a digital external memory aid application (app), called the Digital Memory Notebook. The DMN was developed through an iterative process, working with individuals with cognitive impairment and their care partners. This collaborative development with users resulted in an app that was easy to use for individuals with cognitive impairment. A user-friendly design and supportive text cues placed throughout the app help to support errorless learning and decrease frustration. Following the recommendations of Sohlberg and Matter (1989), we developed a structured clinical intervention alongside the technological development of the DMN, to decrease everyday memory lapses and increase everyday functioning in individuals with cognitive impairment. Prior to starting a clinical trial of the DMN intervention, we piloted the intervention on three participants to illustrate preliminary effectiveness of the intervention and refine the DMN training materials.

At post-testing (i.e., 7 – 9 weeks following the end of the intervention), Cases 1 and 2 self-reported experiencing significant improvement in everyday functioning (IADL-C) and reduction in everyday memory lapses (PRMQ). These findings were supported qualitatively by participant feedback, including self-report of decreased embarrassment when recalling information and increased ability to engage in both practical and leisure-related daily activities due to the ability to depend on recorded information in the DMN. The finding of improved everyday functioning is particularly important as previous cognitive intervention work has often failed to convincingly demonstrate significant changes in self-reported activities of daily living (Ball et al., 2002; see Chandler et al., 2016 for a meta-analysis; Schmitter-Edgecombe & Dyck, 2014) or self-reported everyday memory lapses (Troyer 2008; Dewar, Kapur & Kopel, 2018) in individuals with progressive neurocognitive disorders. For Case 3, self-reported changes in everyday functioning and everyday memory lapses did *not* demonstrate clinically significant change as measured by the RCI at 17 weeks post intervention. Although this could possibly reflect the progressive nature of her Parkinson's disease, other explanations are outlined below. At post-testing, Case 3 was actively using the DMN and described a strong sense of comfort associated with having the DMN as a back-up for her memory. The differing findings between the cases on the functional outcome measures may be related to several factors. First, Cases 1 and 2 demonstrated greater cognitive impairment (Borderline range) and everyday functional difficulties than Case 3. As such, Cases 1 and 2 had more room to demonstrate improvement on the functional measures. Unsurprisingly, none of the participants self-reported normative range functioning on the everyday measures at post-testing due to degree of cognitive impairment. In addition, the follow-up period for Case 3 was longer (17 weeks) compared to the other two cases (7 and 9 weeks), and it is possible that Case 3 might have reported greater improvement at 7 – 9 weeks that could have dissipated with time. During the course of the pilot clinical trial, we will follow participants monthly to examine the course of the intervention effects. Another difference between Case 3 and Cases 1 and 2 was the degree of technical difficulties Case 3 experienced while using the DMN. Case 3 had an earlier version of the DMN app that contained more bugs than the version that Cases 1 and 2 were able to utilize. Furthermore, Case 3 had experienced a stressful multiple week hospitalization just prior to the follow-up and did not have access to her DMN during that time, which could have impacted her follow-up ratings.

Despite the differing findings at post-testing on the measures of everyday functioning, on measures of coping self-efficacy, results indicated universal and clinically significant improvement, with Cases 1 and 3 entering the normative range of coping self-efficacy. These findings were assessed at a post-treatment time that was greater than one month following the end of the intervention, which is significant considering that many intervention effects are short-lived and do not remain at follow-up (Greenaway, Duncan, & Smith, 2012). These findings were also qualitatively supported by participant feedback related to the DMN improving organization and leading to increased feelings of accomplishment, autonomy, and reliability. These findings are especially significant as Smith, Chandler, Fields, Aarke and Locke (2018) found that both individuals with MCI and their caregivers rated self-efficacy, as opposed to functional improvement, mood, and memory ability improvement, as a more important outcome of a memory compensation intervention.

Smith and colleagues (2018) also found that individuals with MCI and their caregivers rated changes in quality of life (QoL) as the most important outcome in memory compensation interventions. They further indicated that only 10% of active MCI clinical trials include QoL as an outcome. The current case study illustrations included QoL and satisfaction with life (SWLS) as outcome measures. We found a significant clinical change in the QoL measure for only one (Case 2) of the three participants. These results are consistent with a meta-analysis conducted by Chandler and colleagues (2017), which found no significant differences in QoL following cognitive interventions for individuals with cognitive impairment. It is possible that cognitive interventions may only exert partial effects on QoL, as QoL is difficult to target due to its complex and multi-faceted nature (Chandler et al., 2017). While QoL is a complex construct that measures various facets related to everyday life satisfaction (e.g., physical health, finances, family relationships), satisfaction with life is a more general measure of life satisfaction, gauging an individual’s feelings of life fulfillment with their life overall. In the current study, Cases 1 and 2 demonstrated clinically significant change on a life satisfaction measure, with Case 1 exceeding the normative range at post-test, and Case 2 entering into the normative range. Although Case 3 did not demonstrate clinically significant change, they did demonstrate a positive change in satisfaction with life at post-test, nearing the normative mean. The SWLS is unique in that respondents can integrate emotional and affective experiences that are important to them when judging overall life satisfaction, instead of responding to specific domains that may have different valences. This allows the SWLS to function as a measure of subjective well-being (Pavot, Diener, Randall, & Sandvik., 1991).

Based on participant feedback and clinical observation of these pilot cases, adjustments to the DMN clinician manual and DMN training manual were made. Consistent with the importance of improving QoL, we recognized that Self Determination Theory (Deci & Ryan, 1985) was an underlying yet indistinct force behind the clinical approach to the DMN. The newer iteration of the DMN training manual, which will be used in a pilot clinical trial, will now explicitly include instruction to promote the three tenants of Self-Determination Theory: autonomy, perceived competence, and relatedness. *Autonomy* is encouraged by having clients assess their own perceived needs and difficulties, along with setting personalized goals based on their own needs and experiences, only receiving guidance from the clinician when necessary. *Perceived competence* is fostered during the intervention by having clients record their strengths and areas of improvement at the start of each session, and by teaching problem-solving. Perceived competence is also fostered by the DMN itself with the addition of milestone accomplishments provided at irregular intervals as positive reinforcers for DMN use. Lastly, *relatedness* is fostered by the relationship between the client and the clinician. Like traditional therapeutic relationships, clinicians are trained to create supportive, honest, and empathic relationships with the client. However, unlike traditional therapeutic relationships, clinicians are encouraged to take an interest in the client's life more generally throughout the intervention and be open to regularly sharing relevant and appropriate personal experiences to foster a reciprocal social relationship. This relatedness was partly fostered in this study by having the intervention take place in the homes of each participant, allowing for the clinician to take an interest in the participant's life more fully than what would be possible in a laboratory or clinical setting.

As a result of this work, we also recognized a need for clinicians and participants to rate participant progress and their competence level at the end of each session. This will allow us to better judge our success in designing an application that can be learned primarily through errorless learning. Since participants are asked to engage in exercises to practice what they learn in each session, it is important to address any confusion or feelings of low self-efficacy prior to ending the session. This has the benefit of reducing the possibility of the participant being unable to engage appropriately in the exercise for that week, as well as reducing the possibility of spending training time in the subsequent session correcting confusion. We also recognized that individuals with more technology experience felt that the earlier sessions of the DMN moved slowly compared to their preferred pace. Although we believe that an individual with more experience with technology could complete the intervention in fewer sessions, we also believe it is important that individuals gain procedural knowledge and learn to adapt the DMN more broadly so that the DMN can be successfully used as impairment progresses. In its current form, the intervention takes a holistic approach to each participant, which requires taking the time to get to know the individual, their environment, and preferred goals. The early sessions are an important bedrock for ensuring individuals can gain the most from the later sessions, as clinicians can integrate what they learn from the participant into guiding the most productive use of the DMN as well as their self-care and brain health goals in later sessions. Of note, these activities were universally enjoyed by all participants in the pilot intervention. We believe it will be important to incorporate this explanation of the session pace more explicitly in the clinical and training materials to ensure participants understand the session pace, particularly for participants with more experience with technology. It will also be of interest to explore whether the intervention can successfully be administered in fewer sessions.

Limitations to the current work include lack of immediate post-intervention data. As such, we do not know whether the follow-up data represent a maintenance of immediate post-intervention scores, an increase, or a decrease. In addition, the DMN iteration in the current study did not have the capability of tracking overall use of the DMN. In future work, we will have the ability to track components of DMN use, including response to alarms, uses and number and types of entries. Long-term tracking of DMN use will also improve understanding of the point at which the DMN app becomes too difficult to use due to progressive neuropathology. Varied follow-up timelines and health factors also made it difficult to determine the nature of the different outcomes between participants (i.e., findings for Cases 1 and 2 versus Cases 3). Case 3, who had an earlier version of the DMN app, also experienced more technical difficulties with the app than Cases 1 and 2, including loss of training alarms. All Cases, however, experienced technical difficulties as the DMN app was not robust enough to support atypical patterns of use that were not identified during bug testing. Example technical difficulties included the DMN app intermittently freezing on the home page and not saving all information recorded in the journal section. The app was subsequently rebuilt for a pilot clinical trial with several features stabilized and new features added (see Raghunath et al., under review). We expect the newer features (e.g., ability to incorporate pictures in notes section) will further increase the effectiveness of the DMN intervention. Furthermore, it is important to highlight that these three cases are not representative of the entire population of individuals with cognitive impairment and therefore generalizability is limited.

Overall, preliminary findings support the effectiveness of our DMN training intervention to support individuals with improving varying aspects of their lives, despite experiencing significant sequela as a result of their cognitive disease or injury. Participants demonstrated clinically significant changes in their ability to cope with problems and build self-efficacy. Two of our participants demonstrated clinically significant positive change in self-reported coping self-efficacy, as well as satisfaction with life, functional ability, and everyday memory lapses. The differences in outcome between Cases 1 and 2 compared to Case 3 may be due to the difference in follow-up time, DMN app version, experienced health issues by Case 3 prior to post-testing or symptom severity. Clinical observations and participant feedback allowed for refinement of the DMN training materials (e.g., addition of review worksheets for both participant and clinician) and clinician manual (e.g., explicit inclusion of self-determination theory) for the clinical trial. Importantly, the clinical trial will include immediate post-testing in addition to monthly delayed post-testing and long-term tracking of daily DMN app use.

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Table 1.

Digital memory notebook training sessions outline.

Session	Components	Primary Purpose/Goal
		ANTICIPATION
Session 1: My Digital Memory Notebook	Memory questionnaire Technology questionnaire DMN Basics	Provide psychoeducation about memory and the benefits of the DMN; identify memory difficulties and technology utilization/comfort; introduce the DMN and its components; identify DMN location and means of traveling with DMN
		ACQUISITION
Session 2: How to use the Time Schedule to Support Recall of Prior Activities	Today Page tutorial/exercise Task description development Calendar introduction Training alarm Using the DMN in public Recording info outside DMN	Teach use of daily log; demonstrate how referring to daily log can aid everyday retrospective memory difficulties; teach strategies for writing meaningful and detailed notebook entries; help identify strategies (e.g., activity completion) or aids (e.g., alarm) that will support frequent DMN use; help client integrate DMN use with other strategies in use; identify and problem solve ways to minimize common stumbling blocks to DMN use (e.g., embarrassment, forget to use it).
		APPLICATION
Session 3: Daily Activity Completion and Engagement in Future Activities	To-do list and scheduling appts. w/self; tutorials and exercises Checking off activities Scheduling future appts. Flagged appointments and alarm reminders	Teach use of the to-do list within today page for creating a list of tasks to complete; discuss how scheduling an appointment with one's self can aid completion of everyday activities; discuss concept of self-care and help identify and schedule in DMN activities to enhance self-care; practice identifying and recording needed information for new appointments (e.g. time, date, directions, things need to bring, etc.); discuss how DMN features can aid with prospective memory difficulties.
		ADAPTATION
Session 4: How to Use Notes to Expand DMN Utility	Rescheduling appointments Notes and journal section tutorial/exercise	Teach system for documenting activity completion and transferring incomplete activities to the next day; individualization of DMN; identify information to be kept in personal notes section (e.g., pill schedule, medical history, birthday list, bus schedule and maps, photos); discuss the benefits of the DMN journaling feature.
Session 5: How to Stay Motivated and use the DMN to Support Long-Term Goals	Maintaining motivation Long terms goals Brain Health Using the DMN to attain long term goals.	Review the motivational features of the DMN and other strategies to maintain motivation to use the DMN; discuss both leisure (e.g., writing autobiography) and practical (e.g., planning for the future) personal goals; explore emotions and minimize issues that may cause problems reaching goals; identify ways to use the DMN to aid in completion of long-term goals and maintenance of brain health.

Table 2:

Effectiveness of the Intervention for Case Study 1

Measure	Pre-Intervention Score	Post-Intervention Score	Difference	Normative Score *M (SD)*	Range of Scores	Test-Retest	RC Score	RCI	Reliable Change?
PRMQ[1]	74	60	−14	38.8 (9.15)	0 – 80	0.89	−3.26	−6.40	Yes
IADL-C[2]	123	88	−35	37.97 (15.48)	27 – 216	0.91	−4.34	−8.48	Yes
CSES[3]	68	110	42	96.94 (20.48)	0 – 130	0.87	4.02	7.89	Yes
SWLS[4]	18	31	13	24.6 (6.9)	5 – 35	0.85	3.45	6.76	Yes
QoL-AD[5]	33	37	4	38.35 (4.88)	13 –52	0.87	1.61	3.14	No

Note: PRMQ = Prospective Retrospective Memory Questionnaire; IADL-C = Instrumental Activities of Daily Living- Compensation; CSES = Coping Self-efficacy Scale; SWLS = Life Satisfaction Scale; QoL-AD = Quality of Life – Alzheimer's disease.

[1] Crawford et al., 2003; N = 551, general adult population (ages 17 – 94; M age = 63.62 SD = 15.59)

[2] Local norms used; N = 146, healthy older adult population (ages 51 – 89; *M* age = 68.29; *SD* = 8.51)

[3] Local norms used; N = 45, healthy older adult population (ages 52 – 86; *M* age = 67.58; *SD* = 7.95)

[4] Pavot et al., 1991; N = 39, older adult population (M age = 74.00, SD = 8.97; SD = 15.59)

[5] Local norms used, N = 53, older care-partner population (ages 48 – 85; *M* age = 65.01; *SD* = 9.11)

Table 3:

Effectiveness of the Intervention for Case Study 2

Measure	Pre-Intervention Score	Post-Intervention Score	Difference	Normative Score *M (SD)*	Range of Scores	Test-Retest	RC Score	RCI	Reliable Change?
PRMQ[1]	71	46	−25	38.8 (9.15)	0 – 80	0.89	−5.83	11.43	Yes
IADL-C[2]	150	54	−96	37.97 (15.48)	27 – 216	0.91	−14.61	−29.22	Yes
CSES[3]	19	51	32	96.94 (20.48)	0 – 130	0.87	3.06	6.00	Yes
SWLS[4]	6	20	14	19.0 (7.6)	5 – 35	0.85	3.37	6.61	Yes
QoL-AD[5]	31	37	6	38.35 (4.88)	13 –52	0.87	2.41	4.72	Yes

Note: PRMQ = Prospective Retrospective Memory Questionnaire; IADL-C = Instrumental Activities of Daily Living- Compensation; CSES = Coping Self-efficacy Scale; SWLS = Life Satisfaction Scale; QoL-AD = Quality of Life – Alzheimer’s disease.

[1] Crawford et al., 2003; N = 551, general adult population (ages 17 – 94; M age = 63.62; SD = 15.59)

[2] Local norms used; N = 146, healthy older adult population (ages 51 – 89; *M* age = 68.29; *SD* = 8.51)

[3] Local norms used; N = 45, healthy older adult population (ages 52 – 86; *M* age = 67.58; *SD* = 7.95)

[4] Corrigan et al., 1998; N = 95, adults with traumatic brain injury (*M* age = 32.40)

[5] Local norms used, N = 53, older care-partner population (ages 48 – 85; *M* age = 65.01; *SD* = 9.11)

Table 4:

Effectiveness of the Intervention for Case Study 3

Measure	Pre-Intervention Score	Post-Intervention Score	Difference	Normative Score *M (SD)*	Range of Scores	Test-Retest	RC Score	RCI	Reliable Change?
PRMQ[1]	54	51	−3	38.8 (9.15)	0 – 80	0.89	0.16	−0.31	No
IADL-C[2]	76	73	−3	37.97 (15.48)	27 – 216	0.91	−0.45	−0.89	No
CSES[3]	67	93	26	96.94 (20.48)	0 – 130	0.87	2.49	4.88	Yes
SWLS[4]	16	23	7	24.6 (6.9)	5 – 35	0.85	−1.85	3.63	No
QoL-AD[5]	25	25	0	38.35 (4.88)	13 –52	0.87	0	0	No

Note: PRMQ = Prospective Retrospective Memory Questionnaire; IADL-C = Instrumental Activities of Daily Living- Compensation; CSES = Coping Self-efficacy Scale; SWLS = Life Satisfaction Scale; QoL-AD = Quality of Life – Alzheimer's disease.

[1] Crawford et al., 2003; N = 551, general adult population (ages 17 – 94; M age = 63.62; SD = 15.59)

[2] Local norms used; N = 146, healthy older adult population (ages 51 – 89; *M* age = 68.29; *SD* = 8.51)

[3] Local norms used; N = 45, healthy older adult population (ages 52 – 86; *M* age = 67.58; *SD* = 7.95)

[4] Pavot et al., 1991; N = 39, older adult population (M age = 74.00, SD = 8.97; SD = 15.59)

[5] Local norms used, N = 53, older care-partner population (ages 48 – 85; *M* age = 65.01; *SD* = 9.11)