Personal digital assistants as cognitive aids for individuals with severe traumatic brain injury: A community-based trial

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Abstract

Objective: The purpose of this study was to examine the efficacy of personal digital assistants (PDAs) as cognitive aids in a sample of individuals with severe traumatic brain injury (TBI).

Method: The group included 23 community-dwelling individuals at least 1 year post-severe TBI, who had difficulties in performing everyday tasks due to behavioural memory problems. Participants were trained by an occupational therapist to use PDAs as cognitive aids and assessed for occupational performance (using Canadian Occupational Performance Measure (COPM)) and participation in everyday life tasks (using Craig Handicap Assessment and Rating Technique–Revised (CHART)) before training and 8 weeks after training concluded.

Results: Statistically significant improvement was noted for self-ratings of occupational performance and satisfaction with occupational performance (COPM); significant improvement in a self-rating of participation was noted (CHART-R).

Conclusion: A brief training intervention utilizing PDAs as cognitive aids is associated with improved self-ratings of performance in everyday life tasks among community-dwelling individuals with severe TBI.

Keywords: Brain injury, cognition, PDA, assistive technology, occupational therapy

Introduction

Behavioural memory deficit is one of the most often-cited complaints among individuals with acquired brain injury [1, 2]. This construct involves working and prospective memory, attention and executive function [3] as they are involved in the performance of everyday activities, such as taking medications, planning and organizing schedules, keeping appointments, performing multi-step tasks and dealing with distractions. Behavioural memory difficulties have been shown to result in decreased functional independence, job opportunities, community inclusion and self-determination [4–8]. Efforts to manage behavioural memory deficits have often involved compensatory methods, including so-called ‘low-tech’ tools, such as sticky notes and calendars, and ‘hi-tech’ devices, such as personal computers.

As computers have become more portable and more powerful over the past decade, their use in compensating for behavioural memory deficit has grown. Three early memory-specific computer programs—the Visions System [9], ProsthesisWare [10] and the Essential Steps System [11]—provided auditory prompts linked to computer-based calendars. Because these products were linked to desktop computers, however, they could not be accessed outside the home, limiting their usefulness. With the emergence of handheld computers, this problem has been resolved. Since their first introduction for
consumer use, researchers have investigated handheld computers as cognitive aids.

A trio of studies utilizing an early personal digital assistant (PDA), the Psion® Organizer, found that: (a) a patient with memory deficits caused by a brain haemorrhage preferred using the Psion® to a day planner [12]; (b) a 22-year old man with a brain injury demonstrated the ability to respond to reminder alarms set by therapists on a Psion® during his inpatient hospitalization, thereby attending therapy and asking for medication on schedule [13]; and (c) 12 outpatients with brain injuries found the Psion® ‘useful’ as a memory aid [14].

The Psion® Organizer is no longer commercially available, having been superceded by the Palm® operating system and Pocket PC personal digital assistants (PDAs) that have become ubiquitous in consumer culture over the past decade. Interestingly, no one has investigated the use of these powerful handheld devices as cognitive aids for brain injury in their off-the-shelf configurations. Instead, researchers have developed innovative compensatory memory software to be added to them. These products include the Planning and Execution Assistant and Trainer (PEAT) [15] and a suite of task management and task sequencing software for Pocket PCs created by Ablelink Technologies, Inc. Studies on PEAT have not yet been reported, but 10 individuals with mental retardation committed significantly fewer errors while performing a multi-step vocational task when using Ablelink’s Visual Assistant software [16] and 12 individuals with mental retardation required less supervision and committed fewer errors when using Ablelink’s Schedule Assistant to complete tasks in a controlled laboratory setting [17]. Another development team tested a different customized reminder system loaded onto two Pocket PC platforms, one utilizing a keyboard and the other a touch-screen and stylus interface. Twelve adult volunteers with acquired brain injury were trained to respond to reminder prompts on the two devices, then loaned each PDA for 2 months, with a 1-month gap between, in counter-balanced order. All 12 participants could remember how to use the devices throughout the trial; most used them daily and found them useful [18].

Researchers have examined other portable electronic devices as cognitive aids. The largest study involved an electronic paging system called ‘Neuropage’ (no longer available commercially). This randomized, controlled, cross-over study comprising 143 participants is the largest ever conducted to assess the efficacy of any cognitive aid. The Neuropage trial utilized a portable electronic pager given to each of the study participants. Over 80% of participants improved their task performance during the 7-week trial phase, as compared to a 7-week baseline [19, 20]. This promising report led to the establishment of a Neuropage service in one English hospital, which reported on 40 outpatients with cognitive impairment, 31 of whom responded to a telephone survey that they found the Neuropage useful as a reminder system [21].

A few pilot studies have examined other portable reminding systems, including cell phones used as pagers [22], a generic paging system [23] and a portable Voice Organizer used to reinforce therapy goals in an inpatient hospital [24] and a community setting [25]. All found that patients were able to perform tasks more consistently when cued by electronic reminders.

Although these researchers have reported on the use of handheld electronics as cognitive orthotics and on disability-specific software designed for PDAs, to date no researchers have reported using unmodified Pocket PC or Palm® PDAs as cognitive aids for individuals with brain injury. Accordingly, the current study utilized two basic, off-the-shelf PDAs, the Handspring Visor® and the Palm Zire 31®, coupled with a brief, home-based training intervention, as cognitive orthotics. Additionally, no research has been reported utilizing behavioural self-rating scales to measure how use of a cognitive aid impacts functional performance. This study does so.

Methods

Purpose

The purpose of this study was to examine the efficacy of PDAs as cognitive aids in a sample of individuals with severe traumatic brain injury (TBI). Two hypotheses were proposed; 8 weeks after the conclusion of training, participants will demonstrate: (1) significantly improved occupational performance of everyday life tasks and satisfaction with their performance, as measured on the Canadian Occupational Performance Measure (COPM) and (2) significantly improved participation in everyday life tasks as measured on the Craig Handicap Assessment and Rating Technique–Revised (CHART-R).

Design

This quasi-experimental study utilized a pre- and post-assessment design. The intervention consisted of providing a participant with a PDA and training her/him in its use as a cognitive aid during three-to-six 90-minute home visits, conducted over no more than a 30-day period. Following this training period, participants were asked to use their PDAs as trained for an 8-week period, during which the investigator
did not contact them. Follow-up assessment was then conducted.

**Participants**

Volunteers were recruited with fliers posted in hospital clinics and community-service programmes in the Commonwealth of Virginia. The study was approved by the Virginia Commonwealth University Institutional Review Board and all volunteers consented to participate. In order to participate, volunteers needed to: (1) have a history of severe TBI no more recently than 1 year prior to enrolment in the study, as certified by a doctor’s letter or medical record; (2) be at least 18 years of age; (3) demonstrate sufficient dexterity to manipulate a stylus used to interact with the PDA; (4) have functional vision and hearing; (5) have a family member or caregiver willing to participate in the assessment element of the study; and (6) have a working home personal computer for backup of PDA data. Additionally, participants needed to demonstrate behaviourial memory impairment on the study instruments. Specifically, they needed to score 27 or lower on the RBMT-E profile scale (a 0–48 scale),^1^ score 75 or lower on the CHART cognitive sub-scale (a 1–100 scale) and describe occupational deficits related to cognitive impairment on the COPM. The only compensation for taking part in the study was that participants were allowed to keep their PDAs, even if they chose not to complete trial participation.

Participants comprised 16 men and seven women ranging in age from 18–66 at time of entry into the study (median 36.5 years). Length of time from injury ranged from 1–34 years (median 7 years). All participants reported prior knowledge of being able to use computers for e-mail and web-surfing. Occupations prior to injury were varied, including student, construction worker, doctor, radio news reporter, forest ranger and a PhD-level engineer, among others. Two secondary school students had returned to school, five participants were working part-time, but no participants had returned to full-time employment post-injury.

On the RBMT-E, the mean score across participants was 22 (range = 10–27). During the COPM interview, each participant self-identified five occupational task deficits in her/his everyday life that were related to memory impairment. Each participant then assigned a number from 1–10 to each task, rating how well he/she performed that task (1 = not at all, 10 = independently) and how satisfied he/she was with that level of performance (1 = very unsatisfied, 10 = completely satisfied). Although participants described individualized problems, upon examination the activities most often cited as occupational deficits fell into the following four general categories: (1) forgetting appointments, (2) time and task management, (3) money management and (4) medication management. A family member or caregiver also participated in the COPM interview. All self-identified task deficits and ratings were agreed to by both the participant and her/his family member or caregiver. The same procedure was followed on post-assessment following the intervention.

The CHART-R was completed jointly by the participant and her/his caregiver, both parties agreeing on answers to the questionnaire, on both pre- and post-intervention assessment. All assessments were conducted by the study investigator.

**Procedure**

The independent variable in this study was the training intervention in the use of a PDA as a cognitive aid. The theoretical basis for this intervention included principles drawn from occupational therapy, person-centred practice and diffusion of innovations theory. Accordingly, the intervention was conducted in participants’ homes and proceeded in a stepwise fashion intended to provide repetition, reinforcement and ongoing facilitation as participants learned to use the PDA to assist in performing everyday life tasks. The intervention built on participants’ familiarity with personal computers and their awareness of other organizational strategies. One-on-one home-based training was conducted by the study investigator, an occupational therapist, verbally and by demonstration. Instructional literature was provided to accommodate varied learning styles.

On the initial visit, the participant was provided with a PDA and shown how to enter data using the stylus. The investigator then loaded Palm® Desktop software onto the participant’s home computer and showed her/him how to enter calendar and alarm entries on the pc-based Palm® Desktop. Participants were then shown how to transfer this information to the PDA via a USB-mediated operation called a ‘hot-sync’. On subsequent visits, participants were taught how to enter appointments directly onto the PDA and how to use the address book feature called ‘Contacts’ and the To Do list feature called ‘Tasks’. Participants were encouraged to transfer appointments, medication schedules and other items from paper-based schedules to the PDA, appending a reminder alarm to each. Additionally, participants were trained in the use of any additional feature they wished to learn (e.g. playing Solitaire on the PDA or downloading digital photos to the PDA).

During the 8-week post-training period, participants were allowed to contact the investigator via
phone or email with trouble-shooting questions, as needed, but the investigator did not initiate any contact with participants. During this period, seven participants contacted the investigator for trouble-shooting assistance.

Findings

All 23 participants completed the study. Findings were entered into SPSS® Version 15 for PC and statistical comparisons were conducted to determine if a significant change in COPM and CHART-R scores may have occurred during the trial.

Findings for each hypothesis were as follows:

Occupational performance and satisfaction with performance change using a PDA

On the COPM, the five self-identified task rating scores from the pre- and post-intervention assessments were averaged for each participant in ‘performance’ and ‘satisfaction with performance’ categories. Aggregate means across participants were then calculated using pre- and post-treatment individual mean scores.

Paired samples t-tests were conducted to compare the pre- and post-assessment aggregate means in both categories, showing statistically significant improvement in performance and satisfaction with performance of everyday life tasks following PDA training (pre-treatment performance mean = 2.86, post-training performance mean = 7.28 (t = 11.36, p < 0.001); pre-treatment satisfaction mean = 1.59, post-training satisfaction mean = 6.73 (t = 9.88, p < 0.001)) see Figure 1.

Change in participation level using a PDA

The CHART-R is a self-assessment rating scale that measures degree of participation in six domains: (1) physical independence; (2) cognitive independence; (3) mobility; (4) occupation; (5) social integration; and (6) economic self-sufficiency. Each of the domains has a maximum score of 100, which is considered the level of performance of an average person without a disability. Repeated measures analysis of variance was used to analyse CHART-R data. Overall CHART-R means showed a significant main effect for before and after training measures (pre-training mean = 74.7, post-training mean = 85, F = 15.9, p < 0.001, \(\eta^2 = 0.42\)). Post hoc pair-wise comparisons were conducted to determine which of the sub-scales were contributing to this significant finding and the conservative Bonferroni correction was applied. Statistically significant results between pre- and post-training sub-scores were found in the domains of cognitive independence (means = 55.5 and 69.4 respectively, t = 5.85, p < 0.001), mobility (means = 87 and 95.7, t = 2.92, p < 0.001) and occupation (means = 63.1 and 78.3, t = 3.18, p = 0.004) see Figure 2.
Discussion

Among the 23 participants, this study demonstrates significantly improved self-estimation of occupational performance in everyday life tasks and in satisfaction with performance, while also demonstrating significantly improved self-ratings for level of participation in the areas of cognition, mobility and occupation. These changes occurred at least 1 year after the participants had sustained a severe TBI, when spontaneous recovery effects are typically considered to have resolved. Accordingly, these findings support the use of a brief, participant-centred and home-based training intervention and the use of consumer-level PDAs as cognitive aids. Whereas TBI research in the past decade has focused primarily on either caregiver programmed devices [9–14, 19–23, 28, 29] or simplified add-on software [15–17], this study provides evidence that individuals with severe TBI-related cognitive impairment can learn to operate off-the-shelf PDAs as assistive technology and improve their self-estimation of functional performance in everyday life tasks by doing so.

When examining a broad construct such as behavioural memory it may be helpful to determine exactly what everyday activities were impacted by the intervention. The COPM is a useful tool for addressing this question, because it requires individuals to self-identify specific occupational difficulties. The problems most often cited by participants—forgetting appointments, time and task management, money management and medication management—may be the problems most impacted by this intervention and clinicians are encouraged to consider PDA training for clients who present with these issues. Further research is recommended to further refine the occupational performance areas best addressed with this approach.

This study shows that occupational performance increases and is maintained—while level of participation is improved—for at least 8 weeks after training, as measured on a pair of self-rating scales. Future investigators may wish to follow participants beyond 8 weeks post-treatment to determine more accurately the lasting impact of this intervention.

All participants in this study used some form of cognitive aid prior to enrolment, the most prevalent being sticky notes and appointment calendars. Using a PDA significantly increased self-ratings of occupational performance above that observed when using low-tech tools, suggesting that PDAs may be more effective than the low-tech pen-and-paper methods traditionally offered in cognitive rehabilitation.

It is important to note that the study sample was neither randomized nor fully representative of the severe TBI population as a whole. Because the sample consisted of adult computer users, who were community-dwelling with intact vision, hearing and dexterity, the results should be applied cautiously for other factions of the TBI population. Future researchers may wish to utilize a randomized, controlled trial with a larger, more inclusive sample.

The assessment measures utilized in this trial, the COPM and CHART-R, are both self-assessment rating scales. Scores for both measures were agreed to by each participant and a family member or caregiver. Including a family member or caregiver in the assessment was intended to provide a degree of objectivity to necessarily subjective self-ratings. The large change in scores on these instruments, however, may indicate a placebo effect, which may be mitigated in future studies by the use of a placebo-treated control group or by separate external observer ratings to verify self-rating estimations.

The effort to develop ecologically valid research for individuals with TBI is still in its infancy and much work needs to be done. As the only extant TBI research on assistive technology for cognition to measure behavioural change with functional self-rating scales, this study confirms previous investigations into the efficacy of portable organizers as cognitive aids and points the way to work that may further clarify the benefits that may be expected from these devices. The intervention described herein is brief, straightforward and inexpensive. This study may provide a guideline for cognitive rehabilitation therapists to pursue in helping their clients live more independent and satisfying lives.

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Note

[1] A widely used test of behavioural memory, the RBMT-E ‘was developed to detect impairment of everyday memory functioning’ [26]. RBMT-E profile scoring includes the following categories: (1) impaired (0–18), (2) poor (19–27), (3) average (28–36), (4) good (37–42) and (5) exceptionally good (43–48). Validity and reliability [27] have been shown to be high. The RBMT-E is often used as a correlative test for validity of other cognitive assessments and RBMT-E scores have been shown to be more ecologically valid than those of traditional psychometric tests of behavioural memory constructs [27].

References


