Improving Daily Life Skills in People with Dementia: Testing the STOMP Intervention Model

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Abstract

People with Alzheimer’s disease and related dementias suffer inevitable losses in the performance of daily life activities. Emerging research demonstrates that improvement in performance may be achievable, yet clinicians lack a standardized approach for evaluation, planning and implementation. The STOMP intervention (Skill-building through Task-Oriented Motor Practice) was created using current knowledge of teaching new behaviours through motor learning principles and task-dependent neuroplasticity which occurs through mass practice and task-specific training. In this quasi-experimental design, we sought to examine the feasibility of the techniques, tolerance of a mass practice schedule and efficacy of the intervention for improving performance in daily life skills and reducing caregiver burden. Our results indicated that participants not only improved in their performance of daily living skills but also maintained the improvement at the three-month follow-up. Mass practice schedules were tolerated by people with mild to moderate dementia. Caregiver burden was unchanged at either follow-up period. Future research examining the advantages conferred from delivering STOMP in the home environment is recommended.

Keywords: Dementia; Alzheimer’s disease; Task-oriented training; Activities of daily living; Motor learning

Background

Maintenance of basic daily life skills, defined here as the ability to take care of oneself and home, are central determinants to older adults remaining in their homes [1]. For people with Alzheimer’s disease and related dementias, the ability to perform daily life skills progressively worsens over time contributing to dependence, institutionalization and mortality [2]. Understandably, researchers have focused dementia research on discovering preventive and curative strategies with less emphasis on research targeting prevention, maintenance or delay of disability in life skills. Yet, elimination or delay of disability in early stages and minimization of disability in mid to later stages through non-pharmacological approaches may be possible. Emerging rehabilitation approaches for people with dementia encompass a variety of techniques (e.g., task-oriented training, strategy training, individualized goal development) and training methods (e.g., errorless learning) which make the direct translation to clinical practice unwieldy without a standardized approach for evaluating client-centred outcomes, planning individualized interventions and implementing training methods [3].

In response to the need for standardized interventions to improve functional performance in people with dementia, the first author (CC) created an individualized, task-oriented training approach called STOMP (Skill-building through Task-Oriented Motor Practice). The STOMP intervention model is a family-centred model with a unique blend of task-oriented training delivered through motor learning principles informed by previous neurobehavioural research from stroke and dementia literature [4,5]. The goal was to create an evidence-informed intervention model for improving daily life skills performance in people with dementia that not only structured the evaluation, but also intervention planning and implementation strategies.

Theoretical foundation

As an overarching theoretical foundation, we turn to a motor rehabilitation theory based on operant conditioning called “learned non-use of motor behaviour”. Taub et al (1998) hypothesizes that people post-neurological injuries demonstrate similar patterns in response to loss of motor function [6]. First, they experience frustration and depression related to the new limitations in movement and function. As a consequence of these emotions, adaptive responses occur. People with neurological injury adapt by compensating for lost skills using whatever remaining skills are available for function. For some, this results in early independence through compensatory methods or movement which may diminish the need for motor recovery [6]. Concurrently, caregivers begin to do the tasks that the patient finds difficult. Collectively, patient emotional reactions, patient compensation and caregiver support for difficult tasks create an environment in which the person responds behaviourally by no longer attempting to move impaired parts of their body, resulting in learned non-use. The consequence of learned non-use is not regaining normal movement. Learned non-use theory implies that motor disability is in part due to the behavioural response to motor changes. Through research, this phenomenon has been reversed using behavioural learning theory techniques that involve shaping new behaviour through sensory rich environments where patients repetitively practice.
movement for a variety of functional activities using a training program called constraint-induced movement therapy (CIMT). Patients practice specific movement or task goals through structured mass practice schedules, three-six hours per day with each goal receiving 30-60 minutes of dedicated practice [6-8]. Mass practice rehabilitation schedules appear to result first in activation of ipsilesional cortical regions and with ongoing robust practice, new axon and dendrite growth [9]. Researchers have postulated that mechanisms of new growth and new circuitry occur because of task-dependent motor plasticity [10-12].

We hypothesize that learned non-use could also explain part of the process of losing daily life skills in people with dementia. As described in previous research, negative changes in life skill performance result in frustration, depression and anxiety for both the person with dementia and their families [13]. Early on, people with dementia compensate for changes in life skills performance by 1) decreasing the frequency of which they do a task or 2) having a loved one perform it for them [14]. Beyond the conscious transference of tasks to family members by the person with dementia, caregivers also begin doing tasks for them because of lack of time in daily schedules, ease of care giving and pain from watching their loved one struggle with tasks. As a result, some disability from dementia could be created by the behavioural response to cognitive changes that affect performance. If this is the case, daily life skills could be improved by shaping desired skills through mass practice, as appears to be the case with other people with different types of neurological disorders [15].

One might argue that a motor recovery theory has questionable applicability for people with cognitive deficits. However, if mass motor practice facilitates behavioural responses and neuroplastic changes in the brain, it follows that mass cognitive practice that is completed by motor practice of tasks could potentially work in the same manner. The potential for neuroplasticity is generally accepted as a possibility for people post stroke [10,16], yet the same potential for neuroplasticity in people with dementia is just emerging [17,18]. Neural plasticity seems heavily predicated on mass practice, yet we currently lack information about the tolerance to or impact of a heavy dosing rehabilitation schedule (three-six hours per day) for people with dementia.

Rationale for evaluation structure

Rehabilitation professionals embrace client-and family-centred practice as the new norm for clinical practice though research has been slow to examine processes for encompassing these ideals within new interventions [19]. Exemplars of incorporating participant goals in dementia research are successful and motivating to the participant [17,20,21]. Caregiver goal prioritization and improvement of improvement may be important for reducing caregiver burden and continued use of techniques after the intervention is complete [22,23]. For this reason, we structured our evaluation to include methods of assessment which facilitated and included 1) participant and family-chosen goals prioritized by importance, 2) examiner-rated performance, and 3) caregiver-rated performance. Inclusion of both examiner and caregiver ratings allows us to objectively measure change in performance while also valuing familial perspectives.

We believe that the success of the STOMP intervention model requires the establishment of a therapeutic relationship beginning with the evaluation and carrying through planning and implementation. The therapist’s ability to establish a therapeutic relationship is a central aspect of the therapeutic process and is considered as much an agent of change as the intervention itself [24]. It is not enough to simply include family goals in an intervention, the therapist must enter the world of the participant, engage them socially and personally, earn their trust and respect, and work collaboratively with them to prioritize and work towards their goals [25]. Empathetic responses and actions demonstrate engagement and genuine belief in the participant as a person with whom you are establishing a relationship and signify to the patient that engagement in therapy is worth their effort [24,25]. In essence, therapist’s using the STOMP evaluation process are directed by family-centred goals which are evaluated from both an examiner and family perspective and is enveloped in the development of a therapeutic relationship with the participant and family from the beginning.

Rationale for planning structure

In planning the intervention, we chose to facilitate attainment of client and family goals through task-oriented training. Task-oriented training involves repetitively practicing impaired skills in contextually appropriate settings with real life objects [10]. Two important understandings of brain behaviour support this choice. First, people who have undergone task-oriented training show evidence of cortical reorganization post-training. Function is restored by adjacent, non-impaired areas making new connections to brain regions needed for specific tasks [10,12]. Second, the use of task-oriented training is supported by procedural memory (subconscious memory for how to do tasks) which is retained into later stages of the dementia and allows researchers to target the cognitive strengths of people with dementia for training [26]. By choosing task-oriented training we may be maximizing learning capacities and priming the brain for neuroplastic change [12].

We structured the delivery of task-oriented training by breaking the tasks down into practice-able steps. Previous researchers have successfully used the task steps as a guideline for training in dementia research [28,29]. Supportive modifications enhance the delivery of task-specific training such as, environmental modifications (e.g., installing a grab bar by the toilet to assist with standing), task modifications (e.g., using a kitchen cart to take plates to the table instead of carrying them), and cognitive strategies (e.g. programming an external alarm to alert someone to take pills [30-32]. When delivered in the context of task-oriented training, these modifications are blended in with the task and steps so that task training seamlessly includes the chosen modifications. In summary, the planning process of the STOMP intervention involves structuring the intervention to achieve individualized goals through task-oriented training with modifications built into practice-able step sequences.

Rationale for implementation structure

To standardize an implementation system for delivering task-oriented training, we created a protocol informed by evidence in instructional design and neuroscience. Motor learning is an instructional method for teaching permanent learning that involves the trainer being conscious of how: 1) practice is scheduled, 2) errors are managed in training, 3) task parameters, such as context and tools, are varied and 4) feedback is delivered [33]. Per Schmidt, people develop cognitive schemas for how movements and activities are performed such that conscious thought is not necessary for
performing a variety of schemas such as getting dressed [33]. Neurological lesions that result in cognitive or motor dysfunction disrupt these previously-encoded schemas and lead to disability. Cognitive capacity, in large part, drives the selection of training parameters to reinstate cognitive schemas through rehabilitation [34,35].

In a person with typical cognitive processes, motor learning theorists assert that new tasks are best taught through random practice (practicing Task A, B, and C in random order), error full learning (allowing the learner to make and learn from his/her mistakes), and variance of the task parameters (e.g., vary the context of training, how they do the task and the tools used to do a task [26,33]). Trainers should provide learners with feedback either intermittently or when the performance falls outside a set criteria for appropriate performance, so that the learner is not reliant on feedback from the trainer to process success and errors [33].

People with dementia learn differently and appear to require different training methods to enhance learning. Researchers have demonstrated that people with dementia learn better through blocked practice (repetitively practicing the same task [A, A, A] or sequence of tasks in a consistent order [A, B, C]) with no variance in task parameters (same environment, same steps, same tools) [33-35]. Errorless learning appears more useful for training daily life skills, particularly when paired with mass practice, as the performance of daily life skills draws upon implicit (unconscious) procedural memory which remains intact longer than explicit (conscious) memory in people with dementia [26,36]. Errorless learning involves creating a training environment in which the person: 1) displays no effort to recall steps of the task and 2) is protected from making mistakes during practice through cues, such as hand-over-hand training verbal, or tactile cues. Repetition is done correctly through errorless learning and cerebrally-encoded in the manner desired for performance [26,37]. Less is known about the types of trainer feedback that supports learning for people with dementia. Some suggest the need for continuous and positive external reinforcement (versus intermittent) to support performance [5,38]. Verbal praise is a viable way of providing feedback even in late stages of dementia when people can respond to positive feedback, through tone of voice and facial expressions [39].

Except for our previously published work [40,41], research using motor learning principles with people with dementia has primarily focused on learning new tasks that were unrelated to life-skills performance [34,42,43]. Therefore, we examined select motor learning principles (blocked practice, continuous verbal feedback, errorless learning and contextually-appropriate environment) as a training paradigm for improving performance of daily life skills.

In choosing a dosage for the STOMP intervention, we turned to previous neuroscience research that examined neurobehavioral outcomes and neuroplastic changes [10,12,35,44]. In the CIMIT studies mentioned earlier, intense dosage schedules of three-six hours per day, five days per week for two weeks produced significant changes in motor behavior, personal satisfaction with improvements and neuroplastic changes in the brain [7,8,44]. Given the paucity of evidence about the dosage requirements to induce neuroplastic changes in people with dementia and the potential for fatigue in an older population, we chose the shorter intensity of three hours a day, while retaining the frequency (five days per week) and duration schedules (two weeks) as a starting point. In summation, the implementation structure (teaching methods and dosage) for the STOMP intervention includes the novel use of motor learning methods to teach daily life skills within mass practice schedules known to facilitate neuroplastic changes in the brain in both progressive and non-progressive, neurological populations [6,12,45]. The STOMP intervention model is outlined in (Table 1).

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Planning</th>
<th>Implementation</th>
</tr>
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<tbody>
<tr>
<td>Individualized goal planning</td>
<td>Real-life tasks broke down into practice-able steps</td>
<td>Training is structured through motor learning principles:</td>
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<tr>
<td>Examiner and caregiver rating of performance</td>
<td>Compensatory modifications built into practice sequences:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a) environmental modification</td>
<td>a) repetitive, blocked practice</td>
</tr>
<tr>
<td></td>
<td>b) cognitive strategies</td>
<td>b) frequent verbal praise</td>
</tr>
<tr>
<td></td>
<td>c) task modification</td>
<td>c) errorless learning</td>
</tr>
<tr>
<td></td>
<td>d) contextually-appropriate environment with real life tools.</td>
<td></td>
</tr>
<tr>
<td>Maintenance of therapeutic relationship throughout each phase</td>
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<td></td>
</tr>
</tbody>
</table>

Table 1: Overview of the STOMP* Intervention Model, *STOMP=Skill-building through Task-Oriented Motor Practice .

Herein, the purpose of our study was to pilot the STOMP intervention model in a sample of people with mild to moderate dementia with three specific objectives. The first objective was to examine the effectiveness of the STOMP intervention to improve daily life skills, as measured by the examiner and as perceived by the caregiver: a) immediately post-intervention, and b) at a 90 day follow-up. Second, we wanted to assess tolerance for a mass practice dosage schedule as measured by negative neurobehavioral responses and qualitative comments that might indicate stress. Finally, we sought to examine change in caregiver burden after participation in the STOMP intervention.

Methods

Study Design

To provide preliminary testing of this intervention, we chose a single group, pre-post design. The principal investigator (PI)
interviewed participants and obtained the descriptive data. Certified interventionist delivered baseline outcome measures one week prior to beginning the 10-day intervention. On the last day of the intervention, the interventionists delivered post-outcome measures. Raters that were blind to pre and post outcomes, reassessed participants with quantitative and qualitative measures 90 days after the trial ended.

The study was approved by our university’s Institutional Review Board.

Participants

The first author recruited participants through a university neurologist, email blasts sent to campus employees, media spots on the radio, TV and newspaper, fliers sent to adult day care facilities and educational sessions provided through several local Alzheimer Association support groups. After eligibility was established, the PI obtained informed written consent by the legally-authorized representative and verbal assent was obtained by the participants in their home.

Inclusion criteria: (1) community-dwelling, English speaking adult (55-90 years old) living with or having frequent contact with a legally-authorized representative; (2) diagnosed with dementia; (3) Mini-Mental Status Examination (MMSE) score >10 but ≤ 25 (indicating mild to moderate dementia); (4) able to understand and follow one-step commands and move one extremity; (5) participant or family member can identify three goal areas related to daily life skills; (6) able to participate in 3 hours of daily intervention in a clinic environment for 2 consecutive weeks. Exclusion criteria: Creutzfeldt-Jakob Dementia, delirium or severe anxiety that may preclude participation.

Descriptive Measures

The PI collected demographic, social and historical data using a socio demographic profile. To describe the level of dementia, we administered the Mini-Mental Status Examination (MMSE) to detect and stage dementia [46]. MMSE cut-off points for mild dementia [21-25] yields a kappa=.62, (p<.001) and moderate dementia (≥10 and<21) yields a kappa=.79, (p<.001 [47]). We examined depressive symptoms using the Cornell Scale for Depression in Dementia (CSDD), a 19-item scale measuring the presence of depression in people with dementia [48]. A cut-off score of 7 yields a sensitivity of .90 and a specificity of .75 for identifying major depression in people with mild-moderate dementia [49].

Outcome Measures

The Canadian Occupational Performance Measure (COPE) is a semi-structured interview and for prioritizing areas of functional performance deficit in three areas: self-care, productivity and leisure in people with a variety of conditions to include dementia [45]. Also used as an outcome measure, the spouse caregiver rated performance on valued tasks (1=worst, 10=best), as well as satisfaction with performance on each task on a scale of 1-10 (1=not satisfied, 10=very satisfied). Clinically-significant change is ≥ 2points [50,51]. In adults with more than one impairment in function, test-retest reliability is adequate (ICC = 0.67) [52].

Based on COPM goals, we observed performance in each goal and then graded potential outcomes using a goal attainment scale. Goal Attainment Scaling (GAS) is an individualized outcome measure of marking goal achievement to track within-subject longitudinal change [53]. The therapist uses the GAS ordinal measure (-2,-1,0,1,2) to break down each COPM goal into five possible scenarios where “0” equals the intended goal, negative scores represent “much less” and “somewhat less” than the expected outcome and positive scores represent “somewhat more” and “much more” than expected outcome. Researchers have successfully used the GAS in combination with the COPM to measure clinical change in adults with traumatic brain injury and dementia [40,53].

To examine changes in caregiver burden, we used the Caregiver Burden Scale (CBS), a 22-item caregiver assessment, to examine burden perception that includes items for health, personal, social and financial well-being [54]. Caregivers rate statements of burden on a continuous scale of “0” indicating never and “4” indicating nearly always. Amount of burden is indicated by adding scores where 0-20 =minimal to no burden; 21-40= moderate burden and >40 =moderate to severe burden. In caregivers of people with dementia, the CBS has good reliability with a Cronbach’s alpha value of 0.93 and intra-class correlation for test-retest reliability of 0.89 [55].

The PI developed a form to track the frequency of negative neuropsychiatric behaviours per task/hour. Neuropsychiatric behaviours included wandering, delusions, hallucinations, inappropriate activity (e.g., taking off clothing unrequested or inappropriate sexual behaviour), purposeless activity, verbal outbursts, physical threats or violence, agitation, sleepiness, tearfulness, anxiety or phobias. A neuropsychiatric behaviour was documented when the presence of the behaviour made the participant stop the task and the interventionist had to refocus the participant to training. The interventionist completed tracking forms during each hour spent with the participant.

The blind evaluators asked one open-ended qualitative question of both participants and caregivers at the 90-day follow-up: “Tell me what being in the STOMP trial was like for you.” In the analysis, we used these answers to support our understanding of participant tolerance of the STOMP intervention, in conjunction with recordings of neuropsychiatric behaviours. In order to assess adherence of the caregiver to the training program post-intervention, we asked, “How often did you practice the STOMP goals at home after the intervention was over?” Three categorical responses were offered which included: none, a little (1-2 days/week), or frequently (≥ 3/week).

Procedure

Each participant was involved in two preparatory sessions prior to beginning their intervention. In the first, the PI administered pre-tests for inclusion criteria and depression in the participant’s home. Per inclusion criteria, the participant and family needed to identify three daily life skills that needed improvement and were meaningful to their everyday lives. For the purpose of this study, daily life skills encompassed activities of daily living (ADL: e.g., bathing, dressing, toileting), instrumental activities of daily living (IADL: e.g., cooking, medication management), or leisure activities (e.g., using the computer or sewing). The second in-home visit was completed by the certified interventionist assigned to the participant one week prior to beginning the intervention. During this visit, the interventionist began developing a therapeutic relationship, solidified family-centred goals, observed goal performance and assessed the environment for features that might support or inhibit performance. Environmental assessment also included taking pictures of the environment to support simulation of environmental set-up in the clinic. The need for caregiver involvement was emphasized by having the caregivers sign a contract...
to encourage use of STOMP techniques in the home environment during and after intervention.

After completion of the in-home evaluations, the STOMP interventionist reviewed strengths and weaknesses that contributed to task performance such as memory, vision or muscle weakness. Based on the participant’s goal, the interventionist considered the participant’s cognitive level, family supports, and the environment to select appropriate modifications that would enhance performance for each goal. Modifications were chosen from three categories: environmental, task or cognitive strategies. These modifications were built into a sequence of “practice-able” steps developed for each goal addressed. Examples of individual goals, modifications and practice-able steps are outlined in (Table 2).

<table>
<thead>
<tr>
<th>Goal</th>
<th>Environmental modification</th>
<th>Task modification</th>
<th>Cognitive strategy</th>
<th>Practice-able steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take medications at correct time</td>
<td>Pill container kept in same location.</td>
<td>Locked pill container with alarm system.</td>
<td>Write a checkmark on calendar as reminder that pills were taken.</td>
<td>1. Respond to alarm.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. Take pills.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Write checkmark on calendar.</td>
</tr>
<tr>
<td>Clean self thoroughly after a bowel movement</td>
<td>Hand-held bidet attached to toilet.</td>
<td>Use of bidet after toileting.</td>
<td>NA</td>
<td>1. Remove pants and sit down.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. Spray self with bidet.</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Dry self with paper.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Wipe down seat.</td>
</tr>
<tr>
<td>Make a cell phone call</td>
<td>Quite, distraction-free environment.</td>
<td>Programmed cell phone numbers into phone.</td>
<td>NA</td>
<td>1. Open phone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2. Dial pre-programmed number.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Talk.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Push hang-up button.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5. Close phone.</td>
</tr>
</tbody>
</table>

Table 2: Examples of individual goals, types of modifications and practice-able steps for STOMP*, STOMP=Skill-building through Task-Oriented Motor Practice

After choosing modifications for each goal area, the interventionists developed the GAS outcome scale. For participants with moderate dementia, interventionists avoided predicting a greater than two level improvement in GAS scores, if the disability was directly related to a cognitive deficit such as attention, memory and organization. Interventionists predicted greater gains if participant performance was immediately supported by a modification, such as the addition of a bath chair or extra lighting. After choosing the modifications and developing the GAS outcome scale, the interventionists purchased up to $250 of equipment and technology needed for each goal and setup the clinic environment similar to the home environment.

The interventionists conducted all treatment sessions in a clinical environment for 3 hours/day, 5 days/week for 2 weeks. One hour was spent practicing each individual goal. At the beginning of each hour, the interventionist introduced the goal and then structured repetitive, blocked practice of each task as many times within the hour as tolerated by the participant. If the participant showed signs of fatigue, we provided short activity breaks with rest or diversion. If the participant displayed a negative neuropsychiatric behaviour that stopped them from practicing the task, we employed a “reframe and refocus” technique. For example, if a participant said, “I can’t believe how badly I am doing on this—I’m never going to get this!” we might reframe the comment by saying, “I am so proud that you are here and you are already doing better!” This was followed by “refocusing” back to task by saying, “Now let’s practice some more.” An errorless learning paradigm was employed so that the participant completed the whole task with as few errors as possible during practice. To do so, interventionists provided hand-over-hand assistance or physical guidance as needed for early sessions but gradually downgraded to fewer physical cues and more gestural and verbal cues. They provided verbal praise indicating good performance at the end of each step within the training sequence.

We invited caregivers to be present for all sessions and requested mandatory attendance for 2 days over the two week intervention for training in the task sequence and cueing strategies. Interventionists provided the caregivers with typed task sequences for each goal by day 2 so that training could occur both at home during the intervention and post-intervention in an effort to facilitate generalization of the learning from clinic to home. Interventionists taught the caregiver how to follow the task sequence using the adaptations and errorless learning. Cuing progressed through a predetermined sequence designed to facilitate caregiver independence in the training (hand-over-hand, tactile cues, and verbal cues).

Intervention Fidelity: Occupational therapy students with one year of professional training completed a 40 hour certification training which included manualized didactic and simulation training focused on the: 1) background and theoretical foundations of the intervention, 2) five hypothesized active ingredients of the intervention(family-centric goals, task-specific training, repetitive, blocked practice delivered with continuous verbal praise, errorless learning, and therapeutic relationship), 3) procedures, and 4) general research training and data check methods. After didactic training, the PI examined the interventionists delivering the intervention in
simulations with people with memory loss in real time and subsequently in greater depth through video. During the simulations, the interventionists used the five active elements to teach volunteers with memory loss a new task. After completion, the PI and peers provided written and verbal feedback to the training interventionist. During the actual intervention, the PI completed fidelity monitoring by having the interventionist complete daily checklists to examine the consistent use of all elements and minimize “drift” from the active elements of the protocol.

Data Analysis
Simple descriptive statistics were created to describe socio demographic and clinical characteristics of the participants. Adherence to the five active ingredients of the intervention is reported by total percentage. For GAS analysis, weighted T-scores were calculated for the pre-, post- and 90 day follow-up scores, based on goal priority [53]. Normality of GAS t-scores, weighted GAS T-scores, COPM scores, and CBS scores was assessed using the Shapiro-Wilk test. Clinically-significant change in the COPM was defined and measured by subtracting the mean post-intervention scores from the mean pre-intervention scores. To examine intervention effectiveness, pre-intervention scores were compared to post-intervention scores and to examine retention of the intervention, post-intervention scores were compared to 90 day reassessment scores. Wilcoxon signed-rank test was used for non-normally distributed variables of interest; while t-tests were used for normally distributed variables. All analyses were performed using SAS® software, version 9.3 of the SAS System for Windows (SAS Institute Inc., Cary NC) with an overall, two-sided alpha level of 0.05.

Results
Nine people consented to participate; three cancelled their participation the week prior to the intervention due to one breaking her hip at home, one suffering a family tragedy involving a granddaughter and one who changed her mind. At the 90 day follow-up, 100% (6/6) participated in reassessment.

Socio demographic and clinical characteristics of the participants (N=6) are summarized in (Table 3). The mean age was 74.7 years, 50% (3/6) were male, 83.3% (5/6) were Caucasian, 83.3% (5/6) were married, and 66% (4/6) were diagnosed with probable Alzheimer’s disease. As determined by the MMSE, 50% (3/6) had mild dementia and 50% (3/6) had moderate dementia. The number treated with medications for dementia was as follows: none (n=2), Excelon (n=2), both Aricept and Namenda (n=1) and both Excelon and Namenda (n=1). Five of six reported taking anti-depressants and also presented with low depressive symptoms; one male refused anti-depressant medications and presented with probable major depression. A single point cane was used by 33.3% (2/6) participants intermittently and 50% (3/6) reported a history of falls. In relation to overall health of the participants as reported by the caregivers, 50% (3/6) was good, 33.3% (2/6) very good and 17% (1/6) was excellent.

Table 3: Sociodemographic and clinical profile of STOMP participants (N=6), MMSE= Mini-mental status examination; CSDD= Cornell Scale for Depression in Dementia

| Race/ethnicity          | 5/6 (83%) Caucasian
|-------------------------|-------------------
| 1/6 (17%) Black         |

<table>
<thead>
<tr>
<th>Education</th>
<th>1/6 (17%) Below HS</th>
</tr>
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<tbody>
<tr>
<td>1/6 (17%) HS</td>
<td></td>
</tr>
<tr>
<td>4/6 (66%) More than HS</td>
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<table>
<thead>
<tr>
<th>Marital status</th>
<th>5/6 (83%) Married</th>
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<tbody>
<tr>
<td>1/6 (17%) Widowed</td>
<td></td>
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<table>
<thead>
<tr>
<th>Type of dementia</th>
<th>1/6 (17%) Vascular</th>
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<tbody>
<tr>
<td>1/6 (17%) Frontotemporal</td>
<td></td>
</tr>
<tr>
<td>4/6 (66%) Probable Alzheimer’s disease</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Cognition</th>
<th>Mean MMSE: 20 (SD 4.0; range: 14-24)</th>
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<table>
<thead>
<tr>
<th>Depressive symptoms</th>
<th>Mean CSDD score: 5.2 (SD 4.4; range: 2-14)</th>
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</table>

Table 4: STOMP pre-, post- and follow-up outcome scores (N=6), COPM=Canadian Occupational Performance Measure; CBS= Caregiver Burden Scale.

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>GAS T-Score</td>
<td>36.78 (36.78)</td>
<td>63.22 (65.42)</td>
<td>54.41 (58.81)</td>
</tr>
<tr>
<td>COPM Performance</td>
<td>3.00 (2.67, 3.67)</td>
<td>7.67 (6.67, 9.33)</td>
<td>7.00 (6.00, 9.33)</td>
</tr>
<tr>
<td>COPM Satisfaction</td>
<td>2.72 ± 1.95</td>
<td>7.89 ± 1.67</td>
<td>3.39 ± 1.02</td>
</tr>
<tr>
<td>CBS</td>
<td>45.83 ± 12.29</td>
<td>46.00 ± 15.15</td>
<td>40.33 ± 15.51</td>
</tr>
</tbody>
</table>

Table 4: STOMP pre-, post- and follow-up outcome scores (N=6) normally distributed variables are reported as mean ± standard deviation; non-normally distributed variables are reported as median (25th quartile, 75th quartile). Values sharing the same superscript within a row do not differ significantly. GAS=Goal attainment scaling; COPM=Canadian Occupational Performance Measure; CBS= Caregiver Burden Scale.

Caregiver-rated COPM scores: Results for caregiver perception of performance and caregiver satisfaction with performance can be found in Table 4. Pre- and post- caregiver perception of performance was tested the STOMP Intervention Model. J Alzheimers Dis Parkinsonism 4: 165. doi:10.4172/2161-0460.1000165
significantly improved (p=.03) and did not significantly change at the 90-day follow-up (p=.28) indicating that caregiver-rated performance remained unchanged. The mean change score for caregiver perception of performance (M=4.67), calculated from the means of pre-intervention (M=3) and post-intervention (M=7.67) scores, represented a clinically-significant change. Pre- and post- caregiver satisfaction with performance also significantly improved (p<.001) and did not significantly change from post-intervention to the 90 day follow-up (p=.31). The mean change score for caregiver satisfaction with performance (M=5.17), calculated from means of pre-intervention (M=2.72) and post-intervention (M=7.89) scores, represented a clinically-significant change. A statistically significant difference was found between pre- and 90-day COPM scores for both performance and satisfaction indicating that any regression in examiner-rated scores is not reflected in caregiver perception scores (p=.05).

Caregiver burden and caregiver practice post-intervention: No significant differences existed in CBS scores between pre and post intervention (p=.97) and post-intervention and 90 day follow-up scores (p=.24). In terms of adherence to practice post-intervention, 66.7% (4/6) caregivers reported frequent practice of the training tasks post-intervention, where 33.3% (2/6) reported that they did not continue to practice the tasks post-intervention.

Negative neuropsychiatric behaviours: Over the course of 180 hours of intervention (3 hours per day for 10 days for 6 participants), the STOMP interventionists documented 70 instances of negative neuropsychiatric behaviour. One participant exhibited 54% (38/70) of the behaviours spanning expressions of anxiety depression, and agitation, as well as verbal outbursts related to one goal that her husband chose for her but that she did not like (setting the table). For the rest of the group, the interventionist recorded 32/70 events, where 81.3% (26/32) were expressions of anxiety, 3% (1/32) for expression of depression and 3.1% (1/32) for agitation with a cell phone not working in the building. One individual displayed the final 12.5% (4/32) behaviours expressed as purposeless activity—obscene head scratching which the caregiver reported was incessantly done at home and actually decreased during the training as the participant was engaged to use her hands during the tasks.

Qualitative feedback about participating in the STOMP intervention:

At 90 days post-intervention, the blind evaluators noted a broad array of comments related to participation. Of the 6 participants, five reported liking and looking forward to seeing their interventionist every day. Two participants made statements noting that “it made me feel like I could still do something” or that “I was worthwhile.” One participant with mild dementia noted that it “changed my life.” He felt that as though the STOMP technique was a method he could apply to current or future areas of disability. Others noted the benefits of being around other people socially.

Caregiver responses included positive responses such as, “he [the participant] is more accepting of my input now and resists me less,” and one caregiver reported decreasing the amount of provider care needed in an assisted living environment that resulted in a significant monthly cost savings. One caregiver noted an improvement in non-practiced physical skills such as endurance and car transfers, stating “I don’t have to pick her leg up to get her into the car anymore.” While most comments were positive, one caregiver expressed frustration when his wife [the participant] was “negative” with the interventionist. This participant had episodes of yelling or throwing plastic dishes. However, he noted that her behaviour improved when we stopped practicing the task she did not like (setting the table) and that in the end, she did perform better in the tasks she wanted to practice. Two caregivers (including the one above who noted his frustration) stated that each shared their positive experiences within their separate dementia support groups and encouraged others to participate in subsequent STOMP trials.

Discussion

In this study, we set out to examine the effect of the STOMP intervention model on daily life skills in people with mild-moderate dementia. We found significant improvement in individualized goals as measured by both the examiner and the caregiver which were maintained at the 90 day follow-up. As a group, the participants seemed to tolerate the high dosage schedule, as evidenced by nominal negative behaviours and positive qualitative responses about participation. Caregiver burden scores were not changed at the end of the intervention or at the 90 day follow-up. Interventionist adherence to the protocol was excellent.

Our success with the use of individualized goal development and focus on real-life skills is confirmed by previous work in community-dwelling people with dementia [56]. In a randomized-controlled trial, Clare et al (2010) demonstrated significant improvement in caregiver ratings of client-selected goals (p<.0001) through a structured cognitive rehabilitation program offered one hour a day, twice a week for eight weeks, compared to relaxation and no treatment groups. The intervention included training in new aids, strategies and techniques for learning new information, techniques for stress management, and practice for improving attention and concentration [20]. In a second RCT, Graff et al (2006) demonstrated success in improving caregiver perception in functional skills through a ten hour caregiver training program which included family goal prioritization, observation of performance in the home and training for compensatory strategies [57].

The retention of these training methods in both RCTs is promising but inconsistent [20,57]. Reported gains made post-intervention in participant-rated gains were not maintained at the 6 month follow-up. Graff et al reported maintenance of examiner and caregiver-rated performance in activities of daily living 12 weeks post-intervention [57]. In our study, examiner and caregiver-rated performance 12 weeks post-intervention were maintained. However, we noted that pre-intervention and 90 day examiner-rated GAS scores were not statistically different, which implies regression towards baseline. We hypothesized factors that may have interfered with retention. First, we trained people in a clinical environment which required transfer of new skills to a different context. Context affects evaluation of daily life skills in people with dementia and may also affect transfer of training [58]. Second, caregivers may not have had adequate training with the sequence or may not have had the time or energy to devote to overseeing the continuation. Third, it is possible that improvements cannot be retained in people with dementia. Through post-hoc analysis, we determined that the participants whose GAS scores approached baseline reported no longer practicing the goal post-intervention. We also discovered that those who practiced as instructed either maintained or improved their final GAS score. These findings indicate that in this small sample, some participants with dementia improved post-intervention using our STOMP task.
sequences for practice. In previous studies of people with stroke and dementia, more time spent in practice led to superior results [8,20].

While the STOMP intervention shares similarities with these studies such as a family-centred practice and the use of compensatory strategies within functional activities [20,57], we pushed the structure of these interventions further by blending in neuroscience evidence for dosage and instructional design evidence for training. In our second aim, we examined the reaction of participants to dosage and instructional design elements of the STOMP intervention which could be fatigueing or aggravating such as intense dosaging, repetitive blocked practice and errorless learning. Overall, we recorded few negative neurobehavioral responses during training that could be directly related to the protocol. Interestingly, the one participant whose negative neuropsychiatric responses contributed to half of the group’s negative reactions was unable to identify her own training goals due to the cognitive-linguistic deficits attributed to her fronto-temporal dementia. Her husband was left to choose goals that may not have been her personal goals. Because this participant did not display negative reactions during training of the other goals (curling hair and using the cell phone) despite the same training regime, we are left to postulate that it was more likely the goal, not the training that caused her reactions. As complimentary data, our qualitative responses supported overwhelming positive feelings about the training and interventionists with no negative remarks concerning dosage or training techniques. These preliminary findings seem to support that people with dementia can tolerate a mass practice schedule with training programs supported by motor learning techniques.

In our last aim, we sought to examine differences in caregiver burden. We found no statistical differences in caregiver burden at either time point. While caregivers commented positively about their involvement in the study and their happiness with participant improvement, it did not cause a decrease in the burden they feel for short and long term responsibilities (e.g., financial) and emotions (e.g., depression) as measured by the Caregiver Burden Scale. A better measure may be one used by Graff which examines caregiver sense of competence in care giving [57,59]. Feelings of competence may have also impacted follow-through post-intervention which resulted in significantly higher competence scores and retained functional performance abilities at the 12 week follow-up [57].

Limitations

It is important to highlight the limitations of the study. First, we piloted this project using a non-randomized, one group design with no control group which limits our ability to infer causality. The second limitation was our use of evaluators. Interventionists evaluated post-intervention outcomes and were therefore not blinded to the process in daily life skills, we found a statistically significant improvement in examiner- and caregiver-reported performance that was retained three months post-intervention. Participants with dementia tolerated intense dosage schedules with nominal expressions of negative behaviour occurring during treatment. Participants and caregivers indicated that participation was enjoyable and for some, transformative in how they consider handling new deficits. In this study, we delivered the STOMP intervention in a clinical environment. We believe that future studies should examine STOMP delivery in the home environment to compare differences in speed and retention of skills to clinic models.

Conclusions/Future Directions

By using the STOMP intervention model to improve performance in daily life skills, we found a statistically significant improvement in examiner- and caregiver-reported performance that was retained three months post-intervention. Participants with dementia tolerated intense dosage schedules with nominal expressions of negative behaviour occurring during treatment. Participants and caregivers indicated that participation was enjoyable and for some, transformative in how they consider handling new deficits. In this study, we delivered the STOMP intervention in a clinical environment. We believe that future studies should examine STOMP delivery in the home environment to compare differences in speed and retention of skills to clinic models.

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References


