FOCUSED QUESTION
Does the Tailored Activity Program (TAP) for dementia patients reduce caregiver burden and neuropsychiatric behavior compared to a wait-list control group as measured by activity engagement, ability to stay on task, behavioral outcomes, depression symptoms, and quality of life.


CLINICAL BOTTOM LINE:
Substantial evidence provided by this study discloses that a client-centered program focused to build upon patients’ preserved cognitive and functional capabilities through activity engagement--a Tailored Activity Program (TAP)--can be used as an intervention in occupational therapy (OT) to increase quality of life in patients with dementia as well as with their caregivers by improving skills, reducing negative behaviors, and decreasing caregiver burden by engagement in activities.

RESEARCH OBJECTIVE(S)
List study objectives.

- Evaluate if the TAP reduces behavioral disturbances in dementia patients compared to a control group.
- Evaluate if the TAP reduces caregiver burden with dementia patients compared to a control group.
- Evaluate if the TAP decreases depressive symptoms associated with caregiver burden.
- Evaluate if the TAP improves quality of life for dementia patients and their caregivers.

DESIGN TYPE AND LEVEL OF EVIDENCE:
Randomized controlled study, Level I
This study used a two-group, controlled, pilot study with 60 dyads (caregiver and patient) randomized to treatment or wait-list control groups.
Limitations (appropriateness of study design):
Was the study design type appropriate for the knowledge level about this topic? Circle yes or no, and if no, explain.

YES/NO

SAMPLE SELECTION
How were subjects selected to participate? Please describe.

Subjects responded to media announcements and mail listings through social services agencies during 2005–2006. Interested participants contacted the research office, were briefed on procedures of the study, and were screened for eligibility by telephone.

Inclusion Criteria

Patients: English speaking, physician diagnosis or MMSE score of <24, able to self feed, able to participate in at least 2 self-care activities.

Caregivers: English speaking, at least age 21 years, living with patient and/or planning to for at least 8 months, willing to learn activity use, willing to participate is >4 hours of daily care.

Exclusion Criteria

Patients with schizophrenia, bipolar disorder, or dementia secondary to head trauma; MMSE score = 0, bed bound (confinement to bed/chair for at least 22 hours daily), or nonresponsive (unable to understand short commands); dementia patient’s boredom, sadness, anxiety, agitation, restlessness, or trouble focusing on a task.

Caregivers who involved in another study, who seeking nursing home placement for the patient, who were terminally ill or in active cancer treatment, or who were hospitalized more than 3 times in the past year.

SAMPLE CHARACTERISTICS

N = 65.

| % Dropouts | 7 % |
| #/ (%) Male | 57% Dementia Patients, 12% Caregiver | #/ (%) Female 43% Dementia Patients, 88% Caregiver |
| Ethnicity | 80% White, 20% African American |
| Disease/disability diagnosis | Dementia |
Check appropriate group:

<table>
<thead>
<tr>
<th>Group</th>
<th>&lt;20/study</th>
<th>20–50/study</th>
<th>51–100/study</th>
<th>101–149/study</th>
<th>150–200/study</th>
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**INTERVENTION(S) AND CONTROL GROUPS**

*Add groups if necessary.*

**Group 1**

**Brief Description**

TAP is based on the reduced-stress threshold model, including vulnerability to environment. TAP is used to match activities to patient’s cognitive and functional abilities to establish routines and reduce caregiver stress. The first 2 home visits, interventionists met with caregivers to introduce goals, addressed daily routines using a semi-structured investigator interview, and identified previous and current activities of interest. Observation by the interventionists focused on communication between caregiver and patient, as well as features of the home environment. Patients were additionally assessed using the Dementia Rating Scale and the Allen’s cognitive assessment.

Additional visits interventionists developed written plans for an identified 3 activities for each client. Caregivers and sometimes patients were given a choice of focus from the listed activities, ranging from multi-step to 1–2 steps to sensory based. Activity was then introduced using role-play. Caregivers were introduced to stress management techniques. Once an activity was mastered, another was introduced. As implementation was mastered, the caregivers were taught how to downgrade to accommodate for future declines.

**Setting**

Home visits to the patient/caregiver home.

**Who Delivered?**

OTs.

**Frequency?**

8 contacts within 4 months, spaced to provide caregivers the opportunity to implement and practice activities in between sessions.

**Duration?**

6 home visits (90 minutes each) and 2 telephone conversations (15 minutes each) over 4 months.

**Group 2**

**Brief Description**

Wait-list control group, \( N = 30 \).

**Setting**

NA

**Who Delivered?**

NA

**Frequency?**

NA

**Duration?**

Scores gathered at baseline, 4 months, and then 8 months.
Intervention Biases: Circle yes or no and explain, if needed.

**Contamination**

<table>
<thead>
<tr>
<th>YES/NO</th>
<th>NR</th>
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**Co-intervention**

<table>
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<tr>
<th>YES/NO</th>
<th>This was included in the exclusion criteria.</th>
</tr>
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</table>

**Timing**

<table>
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<tr>
<th>YES/NO</th>
<th>NR</th>
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</table>

**Site**

<table>
<thead>
<tr>
<th>YES/NO</th>
<th>All visits were done in the natural environment.</th>
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</table>

Use of different therapists to provide intervention

<table>
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<tr>
<th>YES/NO</th>
<th></th>
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**MEASURES AND OUTCOMES**

Complete for each relevant measure when answering the evidence-based question:

Name of measure, what outcome was measured, whether the measure is reliable and valid (as reported in article--yes/no/NR [not reported]), and how frequently the measure was used.

**Behavior using 24 behaviors, 16 from the Agitated Behaviors in Dementia Scale, 2 from the Revised Memory and Behavioral Problem Checklist, 4 from previous research, and 2 identified by families. Caregivers were required to answer occurrence using yes/no and how frequent. Reliability = .86, and validity NR.**

**Cornell Scale for Depression in Dementia, measuring depression symptoms of the patient and caregivers, a 19-item measure focusing on the rating of symptom such as moods and ideational disturbances. This was used on patients and caregivers independently, then combined scores from patients and caregivers were used to form a composite score, 0 = not present, 1 = present, 2 = severe. Reliability = .76, and validity NR.**

**Activity engagement measure developed by the investigator, focused on report of patient engagement in activities by the caregiver using 5 items. Items were scored, with 1= never to 3 = often. Reliability = .54, and validity NR.**

Name of measure, what outcome was measured, whether the measure is reliable and valid (as reported in article--yes/no/NR [not reported]), and how frequently the measure was used.
<table>
<thead>
<tr>
<th>Measure</th>
<th>Outcome measured</th>
<th>Reliability</th>
<th>Validity</th>
<th>How frequently used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life–AD scale</td>
<td>Patients’ quality of life along 12 dimensions, such as energy, mood, memory, and ability to keep busy.</td>
<td>.72</td>
<td>NR</td>
<td>rarely</td>
</tr>
<tr>
<td>Mastery Scale</td>
<td>Caregivers achievement to activity mastery, based on a 5-item Likert scale (1 = never to 5 = always).</td>
<td>.70</td>
<td>NR</td>
<td>frequently</td>
</tr>
<tr>
<td>Zarit Burden Scale</td>
<td>Objective burden of caring for dementia patients, based on a 10-item scale. Items required caregivers to estimate time spent “on duty” or “doing things” for dementia patients.</td>
<td>.89</td>
<td>NR</td>
<td>frequently</td>
</tr>
<tr>
<td>Center for Epidemiological Scale for Depression (CES–D scale)</td>
<td>Caregiver depression was rated by the caregiver using 20-items assessing symptoms in the past week. Scored from 0 = less than 1 day to 3 = 5–6 days.</td>
<td>.91</td>
<td>NR</td>
<td>frequently</td>
</tr>
<tr>
<td>Confidence scale</td>
<td>Confidence in activities done in the past month. Scored from 0 = not confident to 10 = confident.</td>
<td>.72</td>
<td>NR</td>
<td>never</td>
</tr>
<tr>
<td>Subjective burden scale</td>
<td>Caregiver burden associated to upset with behaviors. Scored from 1 = no upset to 8 = extreme upset.</td>
<td>NR</td>
<td>NR</td>
<td>rarely</td>
</tr>
<tr>
<td>Task Management Strategy Index</td>
<td>Patient skill enhancement using a 19-item index. Items focused on the frequency of strategies used, where 1 = never to 5 = always.</td>
<td>.80</td>
<td>NR</td>
<td>rarely</td>
</tr>
</tbody>
</table>

**Measurement Biases**

Were the evaluators blind to treatment status? *Circle yes or no, and if no, explain.*

**YES/NO**  
**NR**
Recall or memory bias. *Circle yes or no, and if yes, explain.*

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<thead>
<tr>
<th>YES/NO</th>
<th>NR</th>
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Others (list and explain):

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<th>NR</th>
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**RESULTS**

List results of outcomes relevant to answering the focused question.

- Include statistical significance where appropriate ($p < 0.05$).
- Include effect size if reported.

Descriptive data included health conditions, self-awareness of health, economic well-being, ADL and IADL physical functioning, and cognitive status. Treatment effects were evaluated at 4 months using ANOVA, to the baseline measurements at the start of the study. Cohen’s $d$ was used as a measure of effect size.

**Caregiver:** 4-month outcomes

- Objective Burden significantly improved for the experimental group, $p = 0.005$, Cohen’s $d = 1.14$, where the hours spent by caregiver doing things for patients was decreased by 1 hour. Hours on duty were also decreased by 5 hours in the experimental group, while the control group reported 2 hours, $p = 0.000$, Cohen’s $d = 1.01$.

- Caregiver mastery, $p = 0.013$, Cohen’s $d = 0.55$, showing that caregivers from the experimental group showed an enhancement in implementing the activities to the patients outside of the intervention session. In addition, an increase in simplification techniques, $p = 0.23$, Cohen’s $d = 0.71$, and improved self-efficacy using the activities was shown, $p = 0.11$, Cohen’s $d = 0.74$.

**Patient:** 4-month outcomes

- Behavioral occurrences, $p = 0.009$, Cohen’s $d = .72$, showing reductions in shadowing and repetitive questioning in the experimental group compared to the control group.

- Activity engagement, $p = 0.029$, Cohen’s $d = 0.61$, showing that caregivers reported an increase in engagement in activities from the experimental group compared to the control group.

- Ability to keep busy, $p = 0.017$, Cohen’s $d = 0.71$, showing that caregivers from the experimental group reported the patient’s ability to stay on task, allowing them more freedom of care, compared to the control group.

- Agitation symptoms, $p = 0.014$, Cohen’s $d = 0.75$, showing a reduction in agitation symptoms reported by caregivers in the experimental group compared to the control group.

- Argumentative behaviors, $p = 0.010$, Cohen’s $d = 0.77$, showing a reduction in argumentative behaviors reported by caregivers in the experimental group compared to the control group.

Results were compared using adjusted mean between the experimental group and the wait-list control group.

Similar patterns were found between the two groups in 2 caregiver outcomes; hours doing care and mastery of activity. In addition, frequency of behaviors showed a similar pattern as well. The control group showed no benefits to level of engagement, caregiver hours on duty, confidence, and simplification as compared to the experimental group.
Was this study adequately powered (large enough to show a difference)? *Circle yes or no, and if no, explain.*

**YES/NO**

Were appropriate analytic methods used? *Circle yes or no, and if no, explain.*

**YES/NO**

Were statistics appropriately reported (in written or table format)? *Circle yes or no, and if no, explain.*

**YES/NO**

**CONCLUSIONS**

State the authors’ conclusions that are applicable to answering the evidence-based question.

The pilot study revealed that the use of TAP produced positive benefits for both caregiver and patient. 69.9% of dementia patients were “very much” engaged in activities with the interventionists, while 67% showed pleasure in participating. 84.8% of caregivers reported the TAP to have a positive effect and found it useful. 100% of the caregivers demonstrated understanding of strategies. Life quality of patients was enhanced, with a large reduction in symptoms. TAP enhanced the ability of patients to achieve pleasure and engagement in activities while reducing behaviors such as agitation or argumentative behaviors and repetitiveness.

Caregivers that used TAP significantly reduced objective burden, which was measured by the amount of time that was put into doing things for the patient. This intervention allowed caregivers to participate and benefit as well. It is suggested that the activities fill a void, enhance role identity, and help with expression in a healthy manner. Simplification of tasks and of the environment allow activity to occur by reducing stress and negative behaviors associated with complexity. TAP offers activities and assessments that provide caregivers with an understanding of the patient’s capacity and limits.

This work is based on the evidence-based literature review completed by Lauren Six, OTS, and Rochelle Mendonca, PhD, OTR/L, Faculty Advisor, University of the Sciences.


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