Tailored Activities to Manage Neuropsychiatric Behaviors in Persons With Dementia and Reduce Caregiver Burden: A Randomized Pilot Study

Laura N. Gitlin, Ph.D., Laraine Winter, Ph.D., Janice Burke, Ph.D., OTR/L, FAOTA, Nancy Chernett, MPH, Marie P. Dennis, Ph.D., Walter W. Hauck, Ph.D.

Objective: To test whether the Tailored Activity Program (TAP) reduces dementia-related neuropsychiatric behaviors, promotes activity engagement, and enhances caregiver well-being.

Design: Prospective, two-group (treatment, wait-list control), randomized, controlled pilot study with 4 months as main trial endpoint. At 4 months, controls received the TAP intervention and were reassessed 4 months later.

Setting: Patients’ homes.

Participants: Sixty dementia patients and family caregivers.

Intervention: The eight-session occupational therapy intervention involved neuropsychological and functional testing, selection, and customization of activities to match capabilities identified in testing, and instruction to caregivers in use of activities.

Measurements: Behavioral occurrences, activity engagement, and quality of life in dementia patients; objective and subjective burden and skill enhancement in caregivers.

Results: At 4 months, compared with controls, intervention caregivers reported reduced frequency of problem behaviors, and specifically for shadowing and repetitive questioning, and greater activity engagement including the ability to keep busy. Fewer intervention caregivers reported agitation or argumentation. Caregiver benefits included fewer hours doing things and being on duty, greater mastery, self-efficacy, and skill enhancement. Wait-list control participants following intervention showed similar benefits for reductions in behavioral frequency and caregiver hours doing things for the patient and mastery. Caregivers with depressed symptoms derived treatment benefits similar to nondepressed caregivers.

Conclusions: Tailoring activities to the capabilities of dementia patients and training families in activity use resulted in clinically relevant benefits for patients and caregivers. Treatment minimized trigger behaviors for nursing home placement and reduced objective caregiver burden. Noteworthy is that depressed caregivers effectively engaged in and benefited from the intervention.

Key Words: Dementia caregiving, activity engagement, disruptive behaviors.
More than 5.1 million Americans have dementia, a progressive and irreversible neurodegenerative disorder, with this number expected to increase to more than 14 million by 2050. Neuropsychiatric behaviors such as apathy, depressed affect, lability, agitation, and aggressiveness are common, with most patients manifesting behaviors with disease progression. Behaviors are the most challenging aspect of caregiving, contributing to caregiver distress, depression, increased care costs, and risk for nursing home placement. Few studies test interventions to minimize behavioral occurrences, and recent research suggests that pharmacologic approaches are not effective and may cause harm. Only a few interventions targeting caregivers report behavioral benefits in patients, whereas most studies do not examine or find symptom reductions. Developing and testing nonpharmacologic approaches to manage behaviors remains an important public health priority.

One promising approach is activity. Research shows that purposeful activity results in reductions of depressive and agitated-type behaviors. However, this research involves nursing home residents, small sample sizes, and nonexperimental designs, and it has not evaluated systematic approaches to developing activities. The paucity of research with community-living patients is significant given that the home is the primary care setting for this population.

This controlled pilot study evaluated the Tailored Activity Program (TAP), which was designed to reduce behavioral disturbances by identifying patients’ preserved capabilities and previous roles and interests, and devising activities that build on them. The trial also tested whether tailored activities enhanced patient engagement, reduced caregiver burden, and improved caregiver mastery, self-efficacy, and use of effective communication and simplification strategies. Because TAP is based on active involvement of caregivers, it may be overwhelming for distressed caregivers. Thus, we examined whether depressed caregivers benefited less than nondepressed caregivers by testing moderating effects of caregiver depressive symptoms on study outcomes.

Using a two-group parallel design, 60 dyads (dementia patients and caregivers) were randomly assigned to treatment or wait-list control. Treatment group participants received TAP, and all dyads were reassessed at 4 months from baseline. At that point, wait-list controls received the TAP intervention and were retested 4 months later (8 months from baseline). This allowed for estimation of effect sizes using a randomized two-group design at 4 months, confirmation of treatment gains for wait-listed participants (4–8 months), and evaluation of program acceptability for all 60 dyads. We hypothesized that relative to controls at 4 months, intervention caregivers would report reduced behavioral occurrences and enhanced activity engagement for dementia patients, and reduced caregiver burden, enhanced mastery, confidence, and skill. We predicted similar benefits for wait-list controls at 8 months.

**METHODS**

**Study Sample and Procedures**

Participants were recruited between 2005 and 2006 through media announcements and social service mailings. Interested caregivers contacted the research office, were explained study procedures, and administered a telephone eligibility screening test. Dementia patients were English-speaking, had a physical diagnosis or Mini-Mental State Examination (MMSE) score and were able to feed self and participate in at least two self-care activities (e.g., bathing, dressing). Patients were excluded if they had schizophrenia, bipolar disorder, or dementia secondary to head trauma, had an MMSE score and were bed-bound (confined to bed or chair) or nonresponsive (unable to understand short commands). Caregivers were English-speaking, 21 years of age, lived with the patient, provided 4 hours of daily care, and reported dementia patient’s boredom, sadness, anxiety, agitation, restlessness, or trouble focusing on a task. Caregivers involved in another study, seeking nursing home placement, terminally ill, in active cancer treatment, or with three or more hospitalizations in the past year were excluded.

Of 84 caregivers screened by telephone, 65 (77%) were eligible, and 60 (92%) were willing to participate. Within 48 hours of baseline, dyads were randomized using random permuted blocks to control for possible changes in subject mix over time. The blocking number, developed by the project statisti-
cian, remained unknown to others. All dyads were interviewed at 4 months by interviewers masked to group assignment and with no intervention role. Of 60 dyads at baseline, four (7%) terminated because of patient death (Fig. 1).

**Intervention Group**

TAP is based on the environmental vulnerability or reduced stress-threshold model, positing that with disease progression, dementia patients become increasingly vulnerable to their environment and experience lower thresholds for tolerating stimuli.\(^\text{23,24}\) The intervention addressed vulnerability by developing activities that matched performance capabilities and decreasing environmental demands to facilitate participation.

TAP involved six 90-minute home visits and two 15-minute telephone contacts by occupational therapists over 4 months. Interventionists met with caregivers, introduced intervention goals, used a semi-structured clinical interview and the Pleasant Event Schedule\(^\text{25}\) to identify previous and current activity interests, observed dyadic communication and home environmental features, and assessed dementia patients using the Dementia Rating Scale\(^\text{26}\) and Allen’s observational craft-based assessments (leather lacquering, placemat task, sensory-based tests).\(^\text{27-29}\) Three activities per patient were developed based on assessments that identified cognitive capacities in areas of memory, language, conceptualization, attention, construction, and initiation, and also evaluated cueing requirements, ability to follow directions and problem solve, and prior interests and roles (e.g., homemaker, carpenter). The interventionist developed a brief written plan (Activity Prescription) specifying patient capabilities, the target activity (e.g., completing a puzzle form board) and goal (e.g., engage in activity 20 minutes daily after breakfast), and implementation techniques (see Appendix). Activities ranged in complexity from multistep (making salad, simple woodworking) to one-to-two step (sorting beads, bean toss game), to sensory-oriented (viewing videos, listening to music). Caregivers, and when appropriate dementia patients, chose one activity prescription to implement initially. The prescription was reviewed and the activity introduced through role play or direct demonstration with patients. Caregivers were instructed in stress-reducing techniques (deep breathing) to establish a calm emotional tone. Once an activity was mastered, another was introduced. In each session, prescriptions were reviewed and modified if necessary. As caregivers

---

**FIGURE 1. Consort Flow Chart of Subject Recruitment and Attrition**

<table>
<thead>
<tr>
<th>No. Screened for Eligibility (N = 84)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible (N = 65)</td>
</tr>
<tr>
<td>Unwilling (N = 5)</td>
</tr>
<tr>
<td>Randomized (N = 60)</td>
</tr>
<tr>
<td>Intervention (N = 30)</td>
</tr>
<tr>
<td>Lost to Follow-up (N = 3)</td>
</tr>
<tr>
<td>Included in 4-month analysis (N = 27)</td>
</tr>
<tr>
<td>Control (N = 30)</td>
</tr>
<tr>
<td>Lost to Follow-up (N = 1)</td>
</tr>
<tr>
<td>Included in 4-month analysis (N = 29)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. Screened for Eligibility (N = 84)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible (N = 65)</td>
</tr>
<tr>
<td>Unwilling (N = 5)</td>
</tr>
<tr>
<td>Randomized (N = 60)</td>
</tr>
<tr>
<td>Intervention (N = 30)</td>
</tr>
<tr>
<td>Lost to Follow-up (N = 3)</td>
</tr>
<tr>
<td>Included in 4-month analysis (N = 27)</td>
</tr>
<tr>
<td>Control (N = 30)</td>
</tr>
<tr>
<td>Lost to Follow-up (N = 1)</td>
</tr>
<tr>
<td>Included in 4-month analysis (N = 29)</td>
</tr>
</tbody>
</table>

---

\(^\text{23}\) Gitlin et al.

Am J Geriatr Psychiatry 16:3, March 2008
mastered activity use, interventionists generalized strategies to care problems and instructed them on how to downgrade activities for future declines.

**Measures**

Background characteristics of dyads included age, income, education, and years providing care measured as continuous variables. Gender, dyadic relationship (spouse or nonspouse), race (white or nonwhite), and marital status (currently married or not married) were measured as dichotomous variables.

**Dementia Patient Outcomes**

The primary outcome was frequency of occurrence of 24 behaviors: 16 from the Agitated Behaviors in Dementia Scale,29 2 (repetitive questioning, hiding or hoarding) from the Revised Memory and Behavior Problem Checklist,30 4 (wandering, incontinent incidents, shadowing, boredom) from previous research showing these behaviors as common and distressful,13 and 2 “others” identified by families that could not be coded elsewhere. For each behavior, caregivers indicated occurrence (yes or no) and, if yes, frequency in past month. Two indices were created: number of behaviors occurring (α = 0.86) and mean frequency of occurrence (main study endpoint). Behaviors reported by caregivers as occurring “constantly” (repetitive questioning) were assigned a score of 300, representing the largest number of reported occurrences across all subjects and behaviors (except for one subject who specified “600” times for one behavior). Two caregivers reported one or more behaviors as “constant” at baseline and seven did so at 4 months. We tested other coding schemes for the “constant” value including recoding the 600 score to 300, and in separate analyses, recoding all “constants” to 600. Because outcomes were similar regardless of coding, we report results for the original coding described above. A secondary outcome was the proportion of caregivers reporting occurrence (yes or no) of each behavior.

We used the 19-item Cornell Scale for Depression in Dementia to rate depressive symptoms.32 The Cornell Scale for Depression in Dementia was administered to dementia patients and caregivers, each of whom responded independently. Composite scores per item were based on combined ratings (0 = not present; 1 = present; 2 = severe) of caregiver and patient. Scores represented the sum of composite scores (Cronbach α = 0.76 for this sample).

Activity engagement was measured using a five-item, investigator-developed index of caregiver report of patient in past 2 weeks (“Enjoyed doing activities”; “Showed signs of pleasure or enjoyment”) from 1 = “Never” to 3 = “Often.” Scores represented mean ratings across five items (with one reverse coded), with higher scores indicating greater engagement (α = 0.54).

We used the well-established 12-item Quality of Life-AD scale to assess caregiver perceptions of life quality in dementia patients.33 Responses ranged from 1 = “Poor” to 4 = “Excellent.” We examined item-level scores for one item in particular, ability to keep busy, and overall mean response, with higher scores indicating better life quality (α = 0.72).

**Caregiver Outcomes**

We used psychometrically sound measures for mastery,34 a five-item Likert (1 = never to 5 = always) scale (α = 0.70); subjective burden, measured as upset with behaviors (1 = no upset to 8 = extreme upset);35 and the 10-item Zarit Burden Scale (α = 0.89); objective burden, measured by caregiver estimate of real time spent “on duty” and “doing things” for dementia patients.37

Caregiver depression was measured by the 20-item CES-D scale38 with symptoms rated as occurring in the past week (0 = less than 1 day to 3 = 5–7 days). Scores represented summed responses, with higher scores indicating greater symptomatology (α = 0.91).

Confidence using activities during the past month (0 = not confident to 10 = very confident) was measured by five investigator-developed items. Scores were averaged across items, with higher mean ratings indicating greater confidence (α = 0.72).

Skill enhancement was measured using the 19-item Task Management Strategy Index.39 Caregivers indicated frequency of strategy (cueing, simplifying routines) use (1 = never to 5 = always). A mean strategy use score was calculated, with high scores indicating greater use (α = 0.80).
Treatment Documentation

For each session, interventionists documented time spent, who participated (caregiver, patient), and number of activities introduced. After the final session, interventionists rated the extent to which patients appeared agitated (not at all, somewhat, very much), resisted participation, demonstrated pleasure, and extent to which caregivers demonstrated understanding of strategies, viewed the intervention as useful, and reported strategy benefits (benefit, no difference or made matters worse).

Data Analysis

Descriptive data included sociodemographic characteristics (age, gender, race, education, relationship), health conditions, self-rated health, economic well-being, cognitive status, depressive symptoms, ADL/IADL functioning, and treatment characteristics. $\chi^2$ and Mann-Whitney tests were used to compare experimental and control dyads on characteristics. Means, standard deviations, and ranges for outcome measures and treatment characteristics were computed.

Main treatment effects for patient behavior and caregiver outcomes at 4 months were examined using analysis of covariance (ANCOVA). To increase precision of treatment comparisons, baseline values, cognitive status and number of patient functional dependencies, caregiver age, gender, education, and relationship to patient were selected a priori as covariates based on previous research showing significant associations between these factors and outcomes. Cohen’s $d$ was determined as a measure of effect size.

The distribution of residuals from the ANCOVAs was examined for outcomes and found to be skewed for overall behavior frequency, frequency of five behaviors (agitation, refusing care, repetitive questioning, hoarding, and shadowing), and objective burden (hours doing things; hours on duty). Log transformations improved distributions.

Additional analyses examined the proportion of caregivers reporting each behavior (occurrence or no occurrence), using logistic regression with covariates described above.

To evaluate differential effects at 4 months based on caregiver baseline depressive symptoms, we used a similar analytic strategy as for main effect models (ANCOVAs with same covariates as described above). We then added an interaction term (treatment group by baseline CES-D score).

To evaluate whether control group participants derived similar benefits to the experimental group after receiving TAP, we compared 4 (T2) to 8 (T3) month scores of controls to baseline (T1) to 4 (T2) month scores of experimental group participants on statistically significant outcomes from main analyses, using the methods described above. We anticipated that the magnitude of the difference between experimental and control group treatment effects would be similar and thus, not statistically significant. SPSS version 15.0 was used with a significance level of 0.05. All analyses were two-sided. Analyses followed intention-to-treat such that all subjects providing data were included in analyses regardless of study participation level.

RESULTS

Dementia patients were primarily male (57%) and white (77%), with a mean age of 79 years. On average they had a MMSE score of 11.6, were dependent in eight instrumental and five basic activities of living. Caregivers were primarily female (88%), white (77%), high school graduates (56%), and spouses (62%) with a mean age of 65 (Table 1).

Treatment Implementation

Consistent with intervention intent, nearly eight contacts were completed, with approximately six sessions face-to-face and two by telephone. Average time spent was 1 hour per home visit and 15 minutes for telephone contacts. Most home contacts (mean: 5.13, SD: 1.36) involved patients and caregivers, and an average of 2.4 (SD: 1.1) activities were introduced. Wait-list controls had similar implementation profiles. An average of $70 per participant was spent (range: $0 –129) for materials (e.g., activity boards, beads, organizing bins).

Four Month Patient Outcomes

We found a treatment effect for frequency of behavioral occurrences overall, $F(1,41) = 7.58$, Cohen’s $d =$
0.72 (Table 2), and two behaviors specifically, shadowing, \( F(1,4) = 58.9, p = 0.003 \), Cohen’s \( d = 3.10 \) and repetitive questioning, \( F(1,22) = 5.94, p = 0.023 \), Cohen’s \( d = 1.22 \), reaching statistical significance (not shown in Table 2) for the 13 and 31 caregivers, respectively, reporting these two behaviors. Experimental caregivers reported greater activity engagement, \( F(1,43) = 5.1 \), Cohen’s \( d = 0.61 \), and ability to keep busy, \( F(1,43) = 6.2 \), Cohen’s \( d = 0.71 \). No effects were found for depressed mood or overall life quality.

Whereas overall number of behaviors reported to occur increased for control patients, the number decreased slightly for TAP participants, although this difference did not reach statistical significance. We did find statistically significant reductions in the number of TAP caregivers reporting agitation, Wald \( \chi^2(1) = 6.0 \), Cohen’s \( d = 0.75 \), and argumentation, Wald \( \chi^2(1) = 6.6 \), Cohen’s \( d = 0.77 \), compared with controls.

### Four Month Caregiver Outcomes

Experimental group caregivers reported fewer hours doing things for patients, \( F(1,42) = 8.8 \), Cohen’s \( d = 1.14 \), approximately 1 hour less, whereas control group caregivers reported 2 hours more by 4

---

**TABLE 1. Demographic Characteristics of Sample**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Wait-list Control (n = 30)</th>
<th>Experimental (n = 30)</th>
<th>Total (n = 60)</th>
<th>Range</th>
<th>( \chi^2 )</th>
<th>Z(^d)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, Mean (SD)(^a)</td>
<td>80.8 (9.5)</td>
<td>78.0 (9.2)</td>
<td>79.4 (9.4)</td>
<td>56.0–96.2</td>
<td>-1.30</td>
<td>0.192</td>
<td></td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>63.3</td>
<td>50.0</td>
<td>56.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>36.7</td>
<td>50.0</td>
<td>43.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>80.0</td>
<td>73.3</td>
<td>76.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>20.0</td>
<td>23.3</td>
<td>21.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0.0</td>
<td>3.3</td>
<td>1.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education (%)(^b)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;HS</td>
<td>60.7</td>
<td>48.3</td>
<td>54.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;College</td>
<td>25.0</td>
<td>37.9</td>
<td>31.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MMSE, Mean (SD)(^c)</td>
<td>12.2 (8.8)</td>
<td>11.0 (7.5)</td>
<td>11.6 (8.1)</td>
<td>0.0–27.0</td>
<td>-0.72</td>
<td>0.473</td>
<td></td>
</tr>
<tr>
<td>ADL, Mean (SD)</td>
<td>8.3 (5.1)</td>
<td>8.7 (4.8)</td>
<td>8.6 (4.7)</td>
<td>1.0–20.0</td>
<td>-0.68</td>
<td>0.495</td>
<td></td>
</tr>
<tr>
<td>IADL</td>
<td>7.4 (1.2)</td>
<td>7.4 (1.2)</td>
<td>7.4 (1.2)</td>
<td>3.0–8.0</td>
<td>-0.84</td>
<td>0.401</td>
<td></td>
</tr>
<tr>
<td>Self-rated health</td>
<td>3.2 (1.0)</td>
<td>3.2 (1.0)</td>
<td>3.2 (1.0)</td>
<td>1.0–5.0</td>
<td>-0.23</td>
<td>0.815</td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, Mean (SD)</td>
<td>67.9 (10.6)</td>
<td>62.8 (11.3)</td>
<td>65.4 (11.1)</td>
<td>47.2–89.7</td>
<td>-1.99</td>
<td>0.047</td>
<td></td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6.7</td>
<td>16.7</td>
<td>11.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>93.3</td>
<td>83.3</td>
<td>88.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>80.0</td>
<td>73.4</td>
<td>76.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>20.0</td>
<td>23.3</td>
<td>21.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0.0</td>
<td>3.3</td>
<td>1.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education (%)(^d)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;HS</td>
<td>24.2</td>
<td>30.0</td>
<td>27.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;College</td>
<td>58.6</td>
<td>53.3</td>
<td>55.9</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>17.2</td>
<td>16.7</td>
<td>16.9</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to Patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>70.0</td>
<td>53.3</td>
<td>61.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonspouse</td>
<td>30.0</td>
<td>46.7</td>
<td>38.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Difficulty, Mean (SD)</td>
<td>2.0 (1.0)</td>
<td>1.7 (0.8)</td>
<td>1.9 (0.9)</td>
<td>1.0–4.0</td>
<td>-1.30</td>
<td>0.195</td>
<td></td>
</tr>
<tr>
<td>Health, Mean (SD)</td>
<td>9.0 (2.0)</td>
<td>1.7 (1.8)</td>
<td>9.0 (2.3)</td>
<td>3.0–12.0</td>
<td>-0.33</td>
<td>0.742</td>
<td></td>
</tr>
<tr>
<td>Health behaviors</td>
<td>3.0 (1.5)</td>
<td>2.8 (1.7)</td>
<td>2.9 (1.6)</td>
<td>0.0–5.0</td>
<td>-0.49</td>
<td>0.625</td>
<td></td>
</tr>
</tbody>
</table>

**Notes:** MMSE: Mini-Mental Status Examination; CSDD: Cornell Scale for Depression in Dementia; ADL: Activities of Daily Living; IADL: Instrumental ADL.

\(^a\)N = 59; \(^b\)N = 57; \(^c\)N = 58; \(^d\)Mann-Whitney test.
months. Experimental caregivers also reported fewer hours on duty, F(1,42) = 15.8, Cohen’s d = 1.01, approximately 5 hours less, whereas control participants reported 2 hours more. Also, experimental caregivers reported greater mastery, F(1,43) = 6.7, Cohen’s d = 0.55, enhanced self-efficacy using activities, F(1,43) = 7.1, Cohen’s d = 0.74, and greater use of simplification techniques, F(1,43) = 5.5, Cohen’s d = 0.71, compared with controls (Table 3). We did not find a statistically significant treatment effect for subjective burden.

Caregiver baseline depressive symptom scores did not moderate treatment outcomes. Depressed (CES-D ≥16; 36.7% of sample), and nondepressed (CES-D <16) caregivers benefited similarly on major outcomes.

### Control Group Outcomes Following Treatment

A comparison of adjusted mean effects between experimental (T1–T2) and wait-list controls (T2–T3) showed similar benefits for behavior frequency, F(1,42) = 2.7, p < 0.105 (adjusted mean effect: −0.25, CI [confidence interval]: −0.42 to −0.08), and caregiver hours doing things for patients, F(1,37) = 0.4, p < 0.547 (adjusted mean effect: −0.04, CI: −0.16–
for the experimental group, control group participants showed no benefits in activity engagement, caregiver hours on duty, confidence, or strategy use.

Acceptability of TAP

For all dyads (N = 60), interventionists reported that 69.6% of patients were engaged “very much,” with 30.4% engaging “somewhat,” 67% expressing or showing pleasure very much, 30.4% showing pleasure somewhat and only 2.2% showing no pleasure. Only 6.5% of patients refused participation, 2.2% appeared agitated and 2.2% appeared upset in one or more sessions. Interventionists reported that 84.8% of caregivers indicated the intervention was very useful, with 15.2% finding it somewhat useful. Also, 89.1% of caregivers indicated the intervention had a positive effect. Only 10.9% indicated that strategies had no effect or made matters worse. Interventionists also reported that 100% of caregivers demonstrated understanding of strategies somewhat or very much. Only 2.2% did not use recommended activities.

CONCLUSIONS

The results of this controlled pilot study suggest positive benefits and large symptom reductions as evidenced by effect sizes for patient and caregiver outcomes. For behaviors, the main outcome, treatment gains were found overall and for frequently occurring behaviors (shadowing, repetitive questioning). Fewer caregivers in intervention reported occurrences of agitation and argumentation, behaviors known to trigger nursing home placement. Additionally, life quality improvements were found with caregivers reporting enhanced ability to derive pleasure and engage in activities for dementia patients. TAP did not minimize patient depressed mood, although change was in the expected direction warranting further examination with larger samples.

As to caregivers, TAP significantly reduced objective burden as measured by time spent caregiving; however, subjective appraisals of burden were not affected, suggesting that to address caregiver upset, an intervention targeting subjective well-being may complement TAP. Additional caregiver benefits included enhancements in skills, mastery, and confidence using activities.

Equally important is that TAP was well tolerated by patients and caregivers as suggested by interventionists’ ratings of engagement in treatment sessions. Although interventionists’ ratings are potentially biased, low attrition and high session participation rates testify to intervention acceptability. Furthermore, depressed caregivers benefited similarly as nondepressed caregivers, suggesting that although TAP was behaviorally demanding, distressed caregivers could participate, learn to use activities, and benefit.

Why does engagement in activities tailored to cognitive capacity and interests of dementia patients reduce behavioral symptoms? One explanation is that activities fill a void, maintain roles, and enable dementia patients to express themselves positively. This promotes continuity in identity and a sense of connectedness and belonging, important to life quality throughout the disease. By introducing simplified activities that capitalized on preserved capabilities and lifelong social roles (e.g., preparing simple meals for homemakers), frustration was minimized and positive engagement afforded. Self-actualization was illustrated by some patients’ remembering interventionists between treatment sessions that occurred weeks apart, creating craft objects for holiday gifts, and seeking to frame placemats made in the assessment.

Another explanation is that the intervention reduces allostatic load, defined as overload of sensory and information processing capacity. Recent conceptualizations of behaviors as reflecting the interplay between neurologic, psychosocial, and environmental factors suggest that external conditions may overload patients’ abilities, which may have negative consequences. Simplifying task and environmental contexts in which activities occur may reduce physiologic stress responses and agitated-type behaviors.

Caregivers may benefit from TAP in several ways. A significant concern and source of distress for families is occupying their relatives and supporting personhood. TAP offered engaging activities, and caregivers could observe immediate benefits. The assessments also provided an understanding of patient capacity.
Finally, caregivers found the tailored activities easy and not time consuming to implement.

Important clinical implications can be derived from this study. The TAP assessment combined neuropsychological and performance-based testing to identify capacities and deficits. Families often under- or overestimate patient abilities and may benefit from the assessment itself. One recommendation may be for referral to an occupational therapist trained in TAP to augment neuropsychological testing, to more adequately inform families of patient capacities. Because TAP preserves functionality by reducing behavioral disturbances, it may be reimbursable under Medicare guidelines and thus is a feasible disease management approach.

Several study limitations warrant caution in interpreting findings. First, the lack of an attention control group makes it impossible to exclude the possibility that demonstrated benefits are due to the time and attention bestowed by interventionists. Second, pilot studies may yield large effect sizes and overestimate treatment benefits. Although our results are promising, further testing of TAP is necessary with larger samples and randomized designs controlling for the attention factor.

Another potential limitation is reliance on caregiver self-report of behavioral occurrences, which may be affected by caregiver mood and perceived study demands. Even so, we used two psychometrically sound measures commonly employed in behavioral and pharmacologic research and clinical contexts that rely on collateral informants. Additionally, research suggests caregiver depressed mood accounts for only about 33% of variance in behavioral ratings. Moreover, obtaining objective behavioral ratings in homes from independent raters may not be feasible. Behavioral events occur day or night, making objective sampling difficult. Having an independent rater in the home imposes additional environmental demand characteristics that may have a reactive effect, particularly for easily agitated or paranoid patients. Asking caregivers to chart behaviors can improve accuracy, but may be too burdensome resulting in noncompliance, missing data, and inaccurate recordings. Thus, reliance on proxy or caregiver report of dementia-related behaviors remains the preferred methodology that is widely used.

In summary, this study provides preliminary evidence that tailoring activities to match residual abilities, previous roles and interests, improves life quality for dementia patients living at home. TAP offers an assessment approach for identifying capabilities from which activities can be developed, reduces behavioral symptoms, and benefits caregivers. As such, TAP provides a systematic nonpharmacologic management approach for minimizing difficult behaviors that warrants further large-scale testing, validation with diverse dyads, and investigation into the underlying physiologic mechanisms accounting for symptom reductions.

---

APPENDIX: SAMPLE ACTIVITY PRESCRIPTION—THE TAILORED ACTIVITY PROGRAM

Today’s date: ____________

Your Husband’s Abilities

- Good hand skills–Able to grasp, release, and throw objects.
- Handles/manipulates objects to gather additional information thru his sense of “touch”
- Follows simple 1 step directions with additional cueing (“pointing” and short verbal cues work best)
- Good attention and tolerance (up to 30 minutes) with activities of interest
- Able to distinguish between size, shape, and feel of objects
- Sustains repetitive actions; needs some assistance to progress to the next step

Recommended Activity: Wood Craft

Activity Goal: Your husband will paint/stain wood boxes with familiar paintbrush for 30 minutes, one time per week.

Simplify the Setting for the Activity

1. Set up the area to enhance your husband’s orientation and success in completing the activity.
2. Remove all objects from dining room table except a protective covering and craft objects.
3. Place one wood box on the table in your husband’s field of vision (within 24 inches)
4. Make sure overhead light is on.

Simplify the Activity
1. Allow sufficient time to complete the “task of the day.” Your husband may only paint or stain wood box for 10–15 minutes. That is okay. He may return to the task after a short break.
2. Provide your husband with one box at a time.
3. Relax standard of performance (there is no right or wrong way).

Enhance Participation
1. Draw on your husband’s ability to engage in repetitive activities.
2. Draw on your husband’s ability to work well with his hands and painting history.
3. Your husband has great “activity tolerance” and sticks with a meaningful activity until his is tired. Monitor level of frustration.

Communicate Effectively
1. As you do naturally, continue to use encouraging remarks as he participates in the activity.
2. Use short, clear and precise instructions.
3. If your husband loses focus, use a calm voice and touch his arm to guide him back to the task. Use praise and encouragement to continue.

Strategies for You
1. Try to relax; take a few deep breaths before introducing the activity as we practiced.
2. Remember, there is no right or wrong way for your husband to do the activity.
3. Feel good about yourself—you are doing a great job.

References
27. Blue T, Allen CK: Allen Diagnostic Module Sensory Motor Stimulation Kit II. Colchester, CT, S&S Worldwide, 1993
44. Kraemer HC, Mintz J, Noda A, et al: Caution regarding the use of pilot studies to guide power calculations for study proposals. Arch Gen Psychiatry 2006; 63:484–489