Effective treatment of behavioral symptoms of dementia and relief of caregiver burden through non-pharmacological interventions and participation in activity

Anne Furey
Pacific University

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Effective treatment of behavioral symptoms of dementia and relief of caregiver burden through non-pharmacological interventions and participation in activity

Disciplines
Occupational Therapy | Rehabilitation and Therapy

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Effective treatment of behavioral symptoms of dementia and relief of caregiver burden through non-pharmacological interventions and participation in activity

Prepared by: Anne Furey  
afurey@pacificu.edu

Date: November 30, 2009

Review date: November 30, 2011

CLINICAL SCENARIO:
Dementia is a progressive and irreversible neurodegenerative disorder that currently affects over five million Americans. This number is expected to rise significantly over the next fifty years, causing a focus in care for individuals with dementia. Alzheimer’s, the leading cause of dementia, has been studied extensively from many points of view (genetic, clinical, neuropsychological, and therapeutic) and very few treatments or medications have been found to effectively alleviate symptoms or behaviors of this disease. Dementia is characterized by functional, cognitive and behavioral deficits which eventually result in the person’s inability to reason appropriately and to care for themselves. Examples of behaviors commonly noted in people with dementia are: agitation, wandering, verbal outbursts, apathy and depression. Also, participation in activity tends to decrease in people with dementia due to the aforementioned deficits. Because of these deficits, often one or more caregivers are involved in the daily activities of the person with dementia. Caregivers are often involved in making important decisions for the clients and therefore are usually involved with medical and therapeutic interventions for the client with dementia in some capacity.

Dementia care should be a priority of occupational therapists as OT’s are able to properly assess stages of dementia and intervene with occupations that are individually meaningful to the client. Therefore, it would be extremely helpful to know what non-pharmacological interventions have clinical relevance with clients who have dementia, how these interventions affect behavioral symptoms in the client and if there is an indirect positive effect on caregiver burden.

FOCUSSED CLINICAL QUESTION: Does participation in activity reduce agitation associated with dementia and indirectly reduce caregiver burden better than medications alone?

SUMMARY of Search, ‘Best’ Evidence’ appraised, and Key Findings:
The evidence was found from the five critically reviewed relevant studies.

-Montessori-based programming leads to improvements in constructive engagement in activities as well as an increase in pleasure in people with dementia. It could be successful and widely implemented across a variety of settings serving persons with dementia if the nursing/activity based staff trained in the intervention schedule the program daily and follow through with the programming (Orsulic-Jeras, S., Judge, K.S., & Camp, C.J., 2000).

-Mild to moderate AD patients, treated with recreational-occupational group activities associated with
psychologic support of both patients and caregivers, exhibit some improvement in behavioral disturbances (Farina, E., Mantovani, F., Fioravanti, R., Rotella, G., Villanelli, F., Imbornone, E., …Postiglione, A., 2006).

-Preliminary evidence exists for the potential of therapeutic touch in dealing with agitated behaviors by people with dementia. Therapeutic touch may be an important intervention that is not costly, can be implemented by family or staff, and may prevent or delay the use of pharmacology and other strategies that may decrease the quality of life of the resident (Hawranik, P., Johnston, P, & Deatrich, J., 2008).

-Occupational therapy can improve the daily performance, communication, sense of competence and quality of life of an older patient with dementia and his or her primary caregiver (Graff, M.J.L., Vernooij-Dassen, M.J.M., Zajec, J., Olde-Rikkert, M.G.M., Hoefnagels, W.H.L., & Dekker, J., 2006).

-The MOHO model guides the types of intervention with which one would use when working with dementia patients and to improve their behaviour and quality of life (Graff, M.J.L., Vernooij-Dassen, M.J.M., Zajec, J., Olde-Rikkert, M.G.M., Hoefnagels, W.H.L., & Dekker, J., 2006).

**CLINICAL BOTTOM LINE:** Nonpharmacological interventions (especially those that are activity-based and individually-designed) can have a significant effect on the reduction of negative behaviors exhibited by people with dementia, regardless of the presence or absence of medications. Intervention in dementia care supports viewing the caregiver as a co-client since so much of his or her life is intertwined with the client’s life. Viewing treatment goals for the caregiver has some evidence that shows effectiveness in improving care.

**Limitation of this CAT:** This critically appraised paper has not been peer-reviewed by another independent person. The search for evidence was not exhaustive; rather, the reviewer attempted to gain a thorough overview of the literature that exists on the topic. The reviewer is a novice and is using this paper as a tool by which to learn the research process.

**SEARCH STRATEGY:**

**Terms used to guide Search Strategy:**

- **Patient/Client Group:** “dementia”
- **Intervention (or Assessment):** “agitation” “occupational therapy” “intervention” “nonpharmacological” “activity”
- **Comparison:** Critical reviews, meta-analyses, randomized controlled trial, randomized controlled studies, nonrandomized controlled studies, case studies
• **Outcome(s):** participation, decreased agitation, improved quality of life, decreased depression

<table>
<thead>
<tr>
<th>Databases and sites searched</th>
<th>Search Terms</th>
<th>Limits used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medline</td>
<td>“dementia”, “occupational therapy”</td>
<td>combine with “and”</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>“dementia” “agitation” “intervention” “nonpharmacological” “behavior” “activity”</td>
<td>Studies published after 2000</td>
</tr>
<tr>
<td>OT search</td>
<td>“dementia” “agitation” “intervention”</td>
<td></td>
</tr>
<tr>
<td>CINAHL</td>
<td>“dementia” “agitation” “intervention” “nonpharmacological” “behavior” “activity”</td>
<td></td>
</tr>
</tbody>
</table>

**INCLUSION and EXCLUSION CRITERIA**

- **Inclusion:**
  - Peer reviewed articles
  - Systematic reviews or meta-analyses
  - Studies that used specific, relevant interventions
  - Patients have some form of dementia
  - Intervention could be applicable to occupational therapy
  - Written in English

- **Exclusion:**
  - Written before 2000
  - Articles containing only pharmacological interventions

**RESULTS OF SEARCH**

Five relevant studies were located and categorised as shown in Table 1 (based on Levels of Evidence, Centre for Evidence Based Medicine, 1998)
### Table 1: Summary of Study Designs of Articles retrieved

<table>
<thead>
<tr>
<th>Study Design/ Methodology of Articles Retrieved</th>
<th>Level</th>
<th>Number Located</th>
<th>Author (Year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randomized Controlled Trials, Randomized Controlled Studies,</td>
<td>I</td>
<td>1</td>
<td>Gitlin, Burke, Chernett, Dennis &amp; Hauck (2008)</td>
</tr>
<tr>
<td>Cohort Study</td>
<td>II</td>
<td>2</td>
<td>Farina et.al (2006)</td>
</tr>
<tr>
<td>Nonrandomized (before and after)</td>
<td>III</td>
<td>1</td>
<td>Orsulic-Jeras, Judge &amp; Camp (2000)</td>
</tr>
<tr>
<td>Qualitative Studies (Grounded theory)</td>
<td>NA</td>
<td>1</td>
<td>Graff, Vernooij-Dassen, Zajec, Olde-Rikkert, Hoernagels &amp; Dekker (2006)</td>
</tr>
</tbody>
</table>

### BEST EVIDENCE

The following study/paper was identified as the ‘best’ evidence and selected for critical appraisal. Reasons for selecting this study were:

- **The relevance the evidence obtained in the research has in answering the PICO question**
- **The potential the evidence has for enhancing the profession of occupational therapy**
- **The evidence obtained in the article applies directly to the focus occupational therapy has on participation in meaningful activities.**

### SUMMARY OF BEST EVIDENCE

Table 2: Description and appraisal of a randomized pilot study by Gitlin, L.N. et. al., 2008

**Aim/Objective of the Study/Systematic Review:**

**Study Design:** The study is a prospective two-group (treatment, wait-list control), randomized, controlled pilot study with four months as a main trial endpoint. At four months, controls received the TAP intervention and were reassessed four months later. The design was appropriate as the authors addressed the ethical issues by creating a wait-list control group. It allowed for a control group as well as allowed for more participants in the research sample.

**Setting:** The intervention occurred in the homes of the dementia patients.
**Participants:** Sixty participants were recruited with mailings and media announcements. Interested caregivers were given a phone eligibility screening test. Dementia clients needed to be English speaking, have a physician’s diagnosis or a MMSE score <24, be able to feed themselves and participate in at least two self-care activities. The mean age of the patients was 79.4 years old. The patients consisted of 63.3% males and 36.7% females. Caregivers needed to be English speaking, over 21 years of age, living with the patient, providing over 4 hours of care a day and not involved in any other studies. The average age of the caregivers was 65.4 years old. Patients were randomized using permuted blocks to control for possible changes in subject mix over time. Four of the sixty participants died before follow up protocol could be met.

**Intervention Investigated**

Control: Dementia patients were placed on a wait list for the experimental group; therefore, this group received no intervention for a four month period of time and the experimental intervention for a four month period of time.

Experimental: The Tailored Activity Program (or TAP) involved six 90-minute home visits (or 9 hrs total) and two phone interviews lasting 15 minutes each over a span of four months. The interventionists were not described in detail. An initial TAP session involved the interventionist meeting with the caregiver to discuss goals, to conduct a semi-structured interview and to go over a Pleasant Event schedule in order to find activity interests. The interventionist would also assess the level of dementia in the patient as well as environmental features of the home. Once completed, the interventionist would create an individualized program involving three activities and goals to complete with the caregiver and dementia patient. Modeling the activity was performed by the interventionist if necessary. The caregiver was trained in relaxation techniques during the sessions. As dementia patients mastered an activity and caregivers mastered activity use with the dementia patients, the interventionists instructed caregivers on downgrading the activity for future declines in the dementia patient and generalizing the strategies to other care problems.

**Outcome Measures**

1) Frequency of occurrence of 24 behaviors: 16 from Agitated Behaviors in Dementia Scale, 2 from Revised Memory and Behavior Problem Checklist, wandering, incontinent incidents, shadowing, boredom, and depressive symptoms
   a) Reported by caregivers in the home setting
2) Activity engagement
   a) A five-item investigator-developed index of caregiver report from 1=Never to 3= Often
3) Quality of life
   a) 12-item Quality of Life-AD scale to assess caregiver perceptions in the home setting from 1= poor to 4= excellent
4) Objective and subjective caregiver burden (using Likert scales)
   a) Objective measure by caregiver estimate of real time spent “on duty” and “doing things” for dementia patients
b) Subjective measure by 10-item Zarit Burden Scale of caregiver report in home setting from 1=no upset to 8=extremely upset
5) Skill enhancement of caregiver
   a) 19-item Task Management Strategy Index of caregiver report in home setting from 1=never to 5=always

Main Findings:

Table 1: Outcomes for Experimental and Wait List Control Group Dementia Patients at Four Months (N=56)

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Exp Mean: Baseline</th>
<th>Exp Mean: 4 months</th>
<th>Control Mean: Baseline</th>
<th>Control Mean: 4 months</th>
<th>Adjusted Mean Effect at 4 months</th>
<th>p</th>
<th>95% CI</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Occurrences</td>
<td>30.5(30.3)</td>
<td>18.8(17.6)</td>
<td>41.5(70.5)</td>
<td>60.8(85.3)</td>
<td>-0.32</td>
<td>.009</td>
<td>-0.55, -0.09</td>
<td>0.72</td>
</tr>
<tr>
<td>Number of behaviors</td>
<td>8.0(3.8)</td>
<td>7.2(4.1)</td>
<td>7.5(4.5)</td>
<td>7.7(3.7)</td>
<td>-0.98</td>
<td>.249</td>
<td>-2.67, 0.71</td>
<td></td>
</tr>
<tr>
<td>CSDD</td>
<td>9.2(5.1)</td>
<td>9.0(4.6)</td>
<td>8.1(4.5)</td>
<td>8.7(4.7)</td>
<td>-1.10</td>
<td>.340</td>
<td>-3.39, 1.19</td>
<td></td>
</tr>
<tr>
<td>Activity engagement</td>
<td>2.1(0.4)</td>
<td>2.3(0.3)</td>
<td>1.9(0.4)</td>
<td>2.0(0.4)</td>
<td>0.22</td>
<td>.029</td>
<td>0.02, 0.41</td>
<td>0.61</td>
</tr>
<tr>
<td>Pleasure in recreation</td>
<td>2.4(0.6)</td>
<td>2.6(0.5)</td>
<td>2.2(0.7)</td>
<td>2.1(0.7)</td>
<td>0.38</td>
<td>.045</td>
<td>0.01, 0.74</td>
<td>0.64</td>
</tr>
<tr>
<td>Quality of life Scale</td>
<td>2.2(0.3)</td>
<td>2.4(0.4)</td>
<td>2.0(0.4)</td>
<td>2.1(0.5)</td>
<td>0.18</td>
<td>.095</td>
<td>-0.03, 0.40</td>
<td></td>
</tr>
<tr>
<td>Ability to keep busy</td>
<td>1.6(0.9)</td>
<td>2.2(0.7)</td>
<td>1.7(0.8)</td>
<td>1.6(0.9)</td>
<td>0.56</td>
<td>.017</td>
<td>0.11, 1.01</td>
<td>0.71</td>
</tr>
<tr>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific Behavior: Agitated</td>
<td>30.4</td>
<td>-2.89</td>
<td>1.18</td>
<td>6.00</td>
<td>0.06</td>
<td>.014</td>
<td>0.01, 0.56</td>
<td>0.75</td>
</tr>
<tr>
<td>Specific Behavior: Arguing</td>
<td>44.6</td>
<td>-2.51</td>
<td>0.98</td>
<td>6.55</td>
<td>0.08</td>
<td>.010</td>
<td>0.01, 0.56</td>
<td>0.77</td>
</tr>
</tbody>
</table>

Table 2: Outcomes for Experimental and Wait List Control Group Caregivers at 4 Months (N=56)

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Exp Mean: Baseline</th>
<th>Exp Mean: 4 months</th>
<th>Control Mean: Baseline</th>
<th>Control Mean: 4 months</th>
<th>Adjusted Mean Effect at 4 months</th>
<th>p</th>
<th>95% CI</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior upset</td>
<td>4.5(1.9)</td>
<td>4.5(1.8)</td>
<td>4.6(3.0)</td>
<td>4.8(2.5)</td>
<td>-0.01</td>
<td>0.984</td>
<td>-1.21, 1.18</td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td>21.0(9.0)</td>
<td>20.3(8.8)</td>
<td>21.3(9.2)</td>
<td>20.6(10.4)</td>
<td>0.75</td>
<td>0.715</td>
<td>-3.36, 4.85</td>
<td></td>
</tr>
<tr>
<td>CES-D</td>
<td>14.6(11.0)</td>
<td>13.1(9.4)</td>
<td>13.2(9.6)</td>
<td>14.3(10.2)</td>
<td>-0.74</td>
<td>0.676</td>
<td>-4.31, 2.82</td>
<td></td>
</tr>
<tr>
<td>Objective Burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours doing for patient</td>
<td>6.3(4.3)</td>
<td>5.4(2.5)</td>
<td>6.2(3.3)</td>
<td>8.6(5.7)</td>
<td>-0.22</td>
<td>0.005</td>
<td>-0.36, -0.07</td>
<td>1.14</td>
</tr>
<tr>
<td>Hours feel on duty</td>
<td>18.2(7.3)</td>
<td>13.4(7.6)</td>
<td>15.5(7.7)</td>
<td>17.6(7.1)</td>
<td>-0.25</td>
<td>0.001</td>
<td>-0.37, -0.12</td>
<td>1.01</td>
</tr>
</tbody>
</table>
The treatment effect reported for the frequency of behavioral occurrences overall, $F(1,41)=7.58$, Cohen’s $d=0.72$, as well as 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 $d=1.22$, indicating statistical significance for the caregivers reporting the 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 depression or quality of life. The overall number of behaviors reported to occur increased for control patients, while the number decreased slightly for TAP participants. This difference did not reach statistical significance. There was a statistical significance in the decrease in number of TAP caregivers reporting agitation and argumentation compared with the control group.

Experimental group caregivers reported fewer hours tending to 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 months. Experimental caregivers also reported fewer hours on duty, $F(1,42)=15.7$, Cohen’s $d=1.01$, approximately 5 hours less, whereas controlled participants reported 2 hours less. Also, experimental caregivers reported greater mastery, enhanced self-efficacy using activities, and greater use of simplification techniques, compared with controls. No statistically significant treatment effect was found for subjective caregiver burden.

### Original Authors’ 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. Depressed caregivers effectively engaged in and benefitted from the interventions given to patients.

The study also concludes that TAP offers an effective assessment approach for identifying the capabilities of the dementia patients with which an individualized activity program can be created. The TAP assessment would be useful in itself (separate from the intervention) for an occupational therapist to use. The authors recommend that OT’s become trained in the TAP assessment and suggest that TAP assessment could be covered by Medicare as a feasible disease management approach because of the programs ability to reduce behavioural disturbances and preserve functionality in everyday tasks.
Critical Appraisal:

Validity: Relevant background literature was reviewed, and the need for the study was justified. The study design was appropriate for the research question due to a wait-list control group being formed and all patients receiving the intervention. No power calculations were performed and ethical procedures were not described. Intervention bias could be present due to medications that some of the dementia patients may be taking. The medications could affect the neuropsychiatric disorders that displayed during the TAP.

The benefits of the study include providing a framework by which home health occupational therapists can use to treat dementia patients as well as their caregivers. This study provides further evidence that caregivers need to be treated as co clients by OT’s when they are planning interventions. Finally, this study can add to evidence that activity based programming and occupational therapy is justified in dementia care.

Several limitations were identified in the study. 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 given by interventionists. Second, pilot studies may yield large effect sizes and overestimate treatment benefits. Finally, using caregiver self-report of the dementia patients can be unreliable given the mood and perceived demands of the caregiver.

This study scored 9 out of 11 on the PEDro scale due to the lack of blinding in therapists and assessors. Although this score could be due to lack of information about the interventionists, the scale indicated high external validity as well as relatively high internal validity.

Interpretation of Results: There is some useful evidence that the TAP reduces the specific behaviors of shadowing and repetitive questioning in patients with dementia versus generalized dementia care. Although one needs to focus studies more specifically on caregivers in dementia care, there is guarded evidence that TAP helps to improve overall self-efficacy in caregivers, reduce time spent helping patients and overall perceived burden.

Summary/Conclusion: The 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 nonpharmacological management approach for minimizing difficult behaviors that warrants further study.
Table x: Characteristics of critically reviewed, relevant studies

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention Investigated</td>
<td>Recreational and occupational activity program</td>
<td>Montessori-based activity program</td>
<td>Community based OT</td>
</tr>
<tr>
<td>Comparison intervention</td>
<td>Generalized dementia care</td>
<td>Regularly scheduled activity program</td>
<td>Generalized dementia care</td>
</tr>
<tr>
<td>Outcomes Used</td>
<td>Disruptive behavior</td>
<td>Constructive engagement in activity, pleasure during participation</td>
<td>Daily functioning of dementia patients, caregiver burden</td>
</tr>
<tr>
<td>Findings</td>
<td>The recreational and occupational activity program decreased frequency of disruptive behaviors in people with dementia</td>
<td>Montessori-based programming led to more constructive engagement in people with dementia as well as perceived pleasure during participation than in regular activity programming</td>
<td>Community OT improved patient’s daily functioning and also reduced caregiver burden</td>
</tr>
</tbody>
</table>

Table xi: Characteristics of included studies

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Intervention Investigated</td>
<td>Sensory integration (snoezelen approach)</td>
<td>Psychological interventions and OT interventions combined</td>
<td>Individualized OT intervention</td>
<td>Entertainment robot (AIBO)</td>
<td>Community based OT</td>
</tr>
<tr>
<td>Comparison intervention</td>
<td>Medication, relaxation techniques, reminiscence therapy</td>
<td>Psychological interventions alone</td>
<td>Generalized dementia care</td>
<td>Toy dog</td>
<td>Generalized dementia care</td>
</tr>
<tr>
<td>Outcomes used</td>
<td>Agitation, aggression, anxiety and pain in dementia patients</td>
<td>Quality of dementia care</td>
<td>Quality of life in dementia patients, caregiver burden</td>
<td>Participation in activity, positive behavioral responses in dementia patients</td>
<td>Quality of life, mood, health status in dementia patients, caregivers sense of control</td>
</tr>
<tr>
<td>Findings</td>
<td>The Snoezelen approach was found to be equally or more effective in</td>
<td>The combined approach of Psychology and OT services combines skills in</td>
<td>Individualized OT intervention is effective for both people with dementia and</td>
<td>Both the toy dog and the AIBO were effective in increasing participation in activity of</td>
<td>The memory notebook reduced the rate of behavioral excesses</td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
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</tbody>
</table>
IMPLICATIONS FOR PRACTICE, EDUCATION and FUTURE RESEARCH

- Other research indicates that a multi-sensory intervention approach may also decrease negative behaviors. Inspired by the sensory integration model, the Snoezelen approach (providing sensory environments or experiences that stimulate primary senses without need for intellectual activity) has been shown to decrease negative behaviors in people with dementia. The approach also allows caregivers to view the behaviors as sensory processing difficulties, thereby leading to changes in the environment to promote engagement in occupations. (Lape, J.E., 2009)

- Occupational therapists can complement the skills of psychologists in understanding behavior and emotion, developing behavioral interventions, supporting team development, and providing psychosocial support to caregivers. (Keough, J., Huebner, R.A., 2000).


- Individualized occupational therapy intervention based on the person-environment fit model appears effective for both caregivers and clients (Dooley, N.R., & Hinojosa, J. 2004).

- An entertainment robot was an effective rehabilitation tool in the treatment of severely demented patients (Tamura, T., Yonemitsu, S., Itoh, A., Oikawa, D., Kawakami, A., Higashi, Y.,...Nakajima, K., 2004).

- Community occupational therapy should be advocated both for dementia patients and their caregivers, because it improves their mood, quality of life, and health status and caregivers’ sense of control over life (Graff, M.J.L., Vernooij-Dassen, M.J.M., Thijsen, M., Dekker, J., Hoefnagels, W.H.L. & OldeRikkert, M.G.M., 2007).

- Use of a memory notebook is associated with a reduction in the rate of behavioral excesses for the dementia patient (Holmes, T., 2000).
REFERENCES


