What strategies have been most effective for preventing burnout for caregivers who provide direct long-term care to family members who suffer from Alzheimer?

Benjamin C. Fenison
Pacific University

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What strategies have been most effective for preventing burnout for caregivers who provide direct long-term care to family members who suffer from Alzheimer?

**Disciplines**
Mental and Social Health | Occupational Therapy

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What strategies have been most effective for preventing burnout for caregivers who provide direct long-term care to family members who suffer from Alzheimer?

Prepared by: bfenison@pacificu.edu

Date: 10-17-2011
Review date: 10-17-2014

CLINICAL SCENARIO:

Currently, dementia is affecting many American adults, their family members, and caregivers who provide them direct long term care. Dementia is one of the most prevalent problems with older adults (Ferri et al., 2005). In 2005, there were 24.3 million people with dementia worldwide, which is projected to grow to 81.1 million by 2040. There is a high demand for people to provide care for individuals that have dementia symptoms. However, there is a large burden of strain associated with the care giving experience. This caregiver strain and burden is often times manifested through depression, anxiety and burnout. It is essential for occupational therapists to know most current and best practice for supporting caregivers and giving them techniques to prevent burnout.

FOCUSED CLINICAL QUESTION: What strategies have been most effective for preventing burnout for caregivers who provide direct long-term care to family members who suffer from Alzheimer?

SUMMARY of Search, ‘Best’ Evidence’ appraised, and Key Findings:

After looking at several different studies which explore different intervention techniques and strategies aimed at elevating caregiver strain, I picked five quantitative studies. Three of these studies were randomized controlled trials and the other two were cross-sectional studies. However the study that I found to be the best evidence to support my clinical question was de Rotrou et al., (2011) randomized controlled study that looked at the effectiveness of psycho -educational intervention programs to reduce caregiver strain. This study proposed that standard anti-dementia medication and psycho–educational programs would improve daily life for the caregiver and the patient.

1. Another randomized controlled trial study investigated the effectiveness of psycho-educational intervention programs on reducing the amount of burden of caregivers. Martin-Carrasco et al.,(2007) main findings were that psycho-educational intervention programs did in fact reduce caregiver burden and enhance quality of life as well as improve the physical and mental health outcomes for caregivers.
2. Gaugler, Roth, Haley, & Mittelman (2008) randomized controlled study looked at counselling and support for caregivers of Alzheimer’s patients to relieve the burden and depression associated with the process of transition to institutionalization.

3. In 2008, Wilks and Croom analyzed a cross-sectional review of self-reported data from direct Alzheimer caregivers. They compared social factors that may contribute to positively influencing caregiver’s self-perception of resilience, to prevent strain and burnout.

4. Karlawish, Casarett, Klocinski, & Clark, (2001) cross-sectional study compared caregiver’s perceived quality of life with the Alzheimer’s patient they were caring for. Also, this study looked at how the caregiver would rate the patient’s quality of life and what the caregiver’s prediction of what they think the patent would rate their own quality of life.

**CLINICAL BOTTOM LINE:** There is a large body of evidence that supports interventions for caregivers to decrease the amount of burnout through psycho-education and social support. In addition, by better educating caregivers about the progression of this disease, they can better develop coping skills and the ability to predict how the progression of the disease will affect them and can even positively affect patient behavior. The caregiver takes on an important role in providing structure and routine in the life of the AD patients. It is important for occupational therapist to address what activities and environments best support care-giving.

**Limitation of this CAT:** This critically appraised topic has been peer-reviewed by one other independent person/lecturer. This has been created by a student in masters of occupational therapy program. Also, an exhaustive literature review has not been conducted.

**SEARCH STRATEGY:**

**Terms used to guide Search Strategy:**

- **Patient/Client Group:** direct caregivers of people who suffer from Alzheimer’s
- **Intervention (or Assessment):** intervention that can be used to prevent caregiver burnout and strain
- **Comparison:** caregivers that do not take precautions for their own caregiver burnout/strain
- **Outcome(s):** depression, physical decline, quality of life, caregiver competence and ability to cope.
### Databases and sites searched

<table>
<thead>
<tr>
<th>Databases and sites searched</th>
<th>Search Terms</th>
<th>Limits used</th>
</tr>
</thead>
<tbody>
<tr>
<td>AgeLine</td>
<td>Caregiver Burnout/Strain and Alzheimer Dementia</td>
<td>Full-text, Human, English language, Since 2000.</td>
</tr>
<tr>
<td></td>
<td>53 results</td>
<td>12 articles thoroughly review.</td>
</tr>
<tr>
<td>CINAHL (EBSCOhost)</td>
<td>Caregiver Burnout/Strain and Alzheimer Dementia</td>
<td>Full-text, Human, English language, Since 2000.</td>
</tr>
<tr>
<td></td>
<td>17 results</td>
<td>6 articles thoroughly review.</td>
</tr>
</tbody>
</table>

### INCLUSION and EXCLUSION CRITERIA

- **Inclusion:**
  Caregivers who provide direct care for patients diagnosed with Dementia/Alzheimer’s.
  Studies that have been published between 2000 and 2011
  Only adult patients & caregivers
  Studies that focus on proactive caregivers strategies to prevent burnout/strain.

- **Exclusion:**
  Studies that primary focus on treatment for Dementia/Alzheimer’s
  Studies that don’t focus on interventions for caregivers with dementia and Alzheimer.

### RESULTS OF SEARCH

#### Table 1: Summary of Study Designs of Articles retrieved

After looking at a variety of different studies that focused on different intervention techniques and strategies which focus on elevating caregiver strain I picked five quantitative studies. Three of the studies are randomized controlled trials and the other two were cross sectional studies.
<table>
<thead>
<tr>
<th>Study Design/Methodology of Articles Retrieved</th>
<th>Level</th>
<th>Author (Year)</th>
</tr>
</thead>
</table>
BEST EVIDENCE

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

- Level II: Randomized controlled trials
- Highest level of evidence that is most related to the research topic
- Significant occupational therapy practice implications
- Most recent study
- The outcomes of this study related to quality of life for caregivers and patients
- Large sample size


SUMMARY OF BEST EVIDENCE

**Aim/Objective of the Study/Systematic Review:** This study looked at multiple benefits of a psycho-educational intervention program for direct caregivers of patients who suffered from Alzheimer/dementia in southern Europe.

**Study Design:** Randomized controlled trials that evaluate 115 caregiver dyads [caregivers and patients] were divided into a control or intervention group. Participant’s outcomes were evaluated three times during the six months of treatment.

**Setting:** During a period of three years participants were recruited from 15 community French memory clinics that served people who suffered from Alzheimer disease.

**Participants:** 167 dyads where each patient had a positive diagnosis of AD according to the DSM 4. The patient–caregiver dyads were recruited from 15 French memory clinics and randomized in two parallel groups. The patients’ ages were form 65 to 90 years of age and they all had been living at home with caregivers for the next 6 months. Another criterion for patient’s participants was that they had to be already on anti-dementia medication for the minimum of three months and the maximum of 18 months. The eligibility to be considered a “caregiver” was that they had to be a spouse, child, or relative that had at least 4 hours of direct care per week for the next 6 months. The caregiver also had to agree to try to apply the motivational interventions at home during the study. Some of the caregivers could not participate because of the following:

- Caregivers could not suffer from a medical or psychological condition that would interfere with their ability to monitor or assist patients at home.
- Caregivers had to attend 8 of the 12 psycho-educational sessions during the duration of the study.
- Caregivers could not suffer from a major anxiety or depression or was getting any type of current psychotherapy.
There were 167 dyads at the beginning of the study. Two dropped out due to inclusion criteria and eight more did not give their consent. 16 did not meet the requirements for baseline assessments, and then additional 26 did not stay throughout the study leaving only assessments of 115 dyads at the end of the study.

**Intervention Investigated**

*Control:* was given standard care and was assessed during baseline, then at the third month (Month 3, End of intervention) and follow up at the sixth month. Dyads that were in the control group were put on a waiting list in order to be offered the psycho-educational program after the study had ended.

*Experimental:* The psycho-educational program (PEP) consisted of structured sessions of two hours once a week for 12 weeks for the intervention group dyad. The program was provided to small groups of six to ten caregivers. The sessions were coordinated by a psychologist-group leader. Before the intervention, psychologists who ran the sessions were offered training and received a CD-ROM presentation of the content of each session allowing them to administer the program in a standardized form. In every session, experienced health professionals provided the caregivers with detailed information on specific aspects of the patient’s disease. The PEP was focused on education, problem-solving techniques and emotional coping strategies, and techniques on how to better manage patient’s behavior. The PEP also focused on more proactive communication skills, crisis management, resource information and practical advice. The sessions were schematized in a structured step-by-step way: information, debriefing, ecological stimulation (ES). After information was presented caregivers shared their individual experiences and events which occurred during the previous week. Solutions which rose from individual experiences had to emerge from the group rather than provided by the coordinator. Dyads that were in the controlled group were put on a waiting list in order to be offered the PEP after the study had ended.

<table>
<thead>
<tr>
<th>Primary measures</th>
<th>Assessment used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients level of dementia</td>
<td>Patient’s outcome measures. The primary outcome was functional status measured on the disability assessment scale for dementia (DAD) (Gelinas et al., 1999).</td>
</tr>
<tr>
<td>Caregivers depression</td>
<td>Montgomery and Asberg Depression Rating Scale (MADRS) (Montgomery and Asberg, 1979)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary measures</th>
<th>Assessment used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s cognitive status</td>
<td>Cognitive status assessed with the Alzheimer Disease Assessment Scale (ADAS-Cog) (Rosen et al., 1984).</td>
</tr>
<tr>
<td>Patients symptoms of</td>
<td>Behavioural disorders assessed with the</td>
</tr>
</tbody>
</table>
psychosis Neuropsychiatric Inventory (NPI) (Cummings et al., 1994).

Caregivers burden measurement the Zarit Caregiver Burden Interview (ZBI) (Zarit and Zarit, 1987)

Caregivers sense of competence sense of competence assessed with the Sense of Competence Questionnaire (SCQ) (Vernooij- Dassen et al., 2003)

Caregiver’s ability to cope and understand Patients dementia.
- Caregiver’s knowledge of patients disease
- Caregiver’s ability to cope
- Care-recipient’s interest in daily activities

These areas were assessed with Visual Analogue Scales (VAS) scoring between 0 and 20. Highest values indicated more positive opinions”. VAS were selected on the basis of results of previous pilot studies (Breuil et al., 1994; De Rotrou et al., 2006).

Main Findings: Patients in the experimental and control group’s results remained consistent and did not change significantly in any outcomes throughout the experiment. However the caregiver’s experimental and control neither decreased nor increased the amount of burden or sense of competence in caregivers. Though the amount of depression symptoms in the control group increased, the experimental group were stable which supports the effectiveness of psycho-educational intervention programs for caregivers to decrease depression. In addition, at the end of the study caregivers in the experimental groups showed a significant increase in disease understanding and improvement in ability to cope with the disease compared to the controlled group.

For main analyses, case-complete analyses were performed and comparisons between groups were determined by using an $\chi^2$ test, t-test or Wilcoxon test and comparisons within the groups were determined by using paired t-test or Wilcoxon matched pairs test.

<table>
<thead>
<tr>
<th>measure</th>
<th>baseline 0-months p-value</th>
<th>End of study at 3-months p-value</th>
<th>Follow up at 6-months p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pt level of dementia</td>
<td>0.58</td>
<td>0.15</td>
<td>0.43</td>
</tr>
<tr>
<td>Pt cognitive status</td>
<td>0.14</td>
<td>0.12</td>
<td>0.25</td>
</tr>
<tr>
<td>PT symptoms of psychosis</td>
<td>0.40</td>
<td>0.92</td>
<td>0.57</td>
</tr>
<tr>
<td>Caregivers depression</td>
<td>0.42</td>
<td>0.21</td>
<td>0.14</td>
</tr>
<tr>
<td>Caregivers sense of competence</td>
<td>0.75</td>
<td>0.43</td>
<td>0.46</td>
</tr>
<tr>
<td>Caregivers burden measurement</td>
<td>0.61</td>
<td>0.55</td>
<td>0.25</td>
</tr>
<tr>
<td>Caregiver’s ability to cope</td>
<td>0.53</td>
<td>0.007</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>cope</td>
<td></td>
<td></td>
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<td>------</td>
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</tr>
<tr>
<td>Caregiver’s ability to understand Patient’s dementia</td>
<td>0.80</td>
<td>0.15</td>
<td>0.02</td>
</tr>
</tbody>
</table>


**Original Authors’ Conclusions** Psycho-educational interventions programs can improve caregiver’s perception and expectation of how the disease will affect the patient. This appears to help the caregiver with difficulties that arise and more tools to cope. Also more research must be done to find even better assessments and intervention that are more tailored to fit diverse caregiver personality types. These types of tools may allow better functioning relationships between caregivers and AD patients.

**Critical Appraisal:**

**Validity**

The researchers focus on their clinical question and compiled broad and in-depth literature search on previous caregiver’s psycho-educational research. This study was based on a pervious pilot study compiled by the same team of researchers which does lend to some bias of because of favourable psycho-educational interventions programs. This study presented how previous research of psycho-educational interventions programs for caregivers are successful in preventing depressive symptoms in caregivers and that they were beneficial for both the caregivers and for the patient. Informed consent was given and all ethical procedures were explained to caregivers and patients. Also the controlled group that did not receive psycho-educational programs during the study, but were offered these services once the study was over. This study proposed that a combination of anti-dementia drug therapy, and caregiver education would improve the patient’s quality of function in daily living activities as well as improving patient cognition. The researchers in this study used reliable measurements to assess the psychosocial aspects of the caregiver and patients, but did not use any valid assessment for patients functioning in daily living activities. PEDro score 6 -10

**Interpretation of Results:** The results of this study showed that psycho-educational interventions do not effect the amount of burden on caregivers or their sense of competence in giving care. The results did however, support previous research that psycho-educational intervention can make a significant difference in elevating depression and ability to cope when in distress due to burden. The findings also suggest that education about patient’s disease and progression is an important factor in coping and preventing depression. Some of the limitations of this study are that they did not have an effective measurement for patients function in daily living activities which was one of the research questions. The patients in the experimental and control
groups results remained consistent and did not change significantly in any outcomes throughout the experiment, which means that the study results failed to answer one of the research questions about the patients. However, there were positive results for the caregivers groups.

**Summary/Conclusion:** This study adds to the large amount of evidence of positive effects of education and support for caregivers is essential for buffering strain and depression associated with the burden of caring for people that suffer from AD and dementia. These factors should be considered when occupational therapists are treating individuals with AD.

<table>
<thead>
<tr>
<th>Table: Characteristics of included studies:</th>
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<tbody>
<tr>
<td>(Martín-Carrasco et al., 2007)</td>
</tr>
<tr>
<td>(Gaugler, Roth, Haley, &amp; Mittelman, 2008)</td>
</tr>
<tr>
<td>(Karlawish, Casarett, Klocinski, &amp; Clark, 2001)</td>
</tr>
<tr>
<td>Intervention investigated</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Comparison intervention</td>
</tr>
<tr>
<td>Findings</td>
</tr>
</tbody>
</table>

Prepared by Benjamin C. Fenison, OTS (10-8-2011). Available at http://commons.pacificu.edu/otcats
**IMPLICATIONS FOR PRACTICE**

- There is a large body of research that suggests that social support and education are key buffers for caregiver burnout and strain. Because AD/dementia is a progressive disease is very difficult to prevent strain or burn out, but there are ways to plan and educate caregivers on what to expect so they can plan and address problems before they are evident.

- It is important for occupational therapists to take into consideration the large role that the caregivers take on and how this role can largely affect the quality of lives of patients and caregivers. This means that including the caregiver in the intervention process is as equally important as providing better care for the patient.

- It is important attend to the quality of life of the caregiver and addresses the high potential of depression associated with the strain of care-giving for people with dementia or Alzheimer’s. This can be done by teaching caregivers validation and redirection communication skills and seeking out support groups for caregivers.

**EDUCATION**

- Occupational therapists should educate AD caregivers about the benefits of meaningful occupations and the importance of staying physically active and how these physical activities can buffer against depressive symptoms.

- It is important to present how helpful peer caregiver support groups can be for social support to prevent burnout.

- OT must educate caregivers about the benefits associated with better communication techniques. Educating caregivers’ about the significance of validating patient’s emotions and beliefs all while maintaining patient’s dignity is important. Also teaching caregivers about validation therapy as an aspect of communication that speaks to the patient’s beliefs and "reality" even if caregiver’s reality is much different.

- It is also important to educate caregivers about how dementia patient’s perspective may change over time. This can help the caregiver prepare and plan for what behavior changes that may accrue when observing the progression of this disease. By educating the caregiver about how the patient’s perspective may change over time may prepare the caregiver to better understand why these changes are accruing and this may decrease the distress of these changes.

- It is important for OT’s to teach caregivers how simple routines are very helpful in giving people with dementia daily structure and prevent sun-downing. By teaching caregivers how to simplify tasks and techniques of decreasing frustration, this will further insure better cohesion between the relationship of the caregiver and patients and prevent burnout.
• Finally, it is important for OT to educate caregivers about the stages and progression of the disease, so they can plan for future problems, better environments and clearer expectation of what will come next. Furthermore, OT’s must look at each caregiver and patient’s unique occupational profile and use their clinical judgment to decide what factors and environments best support care giving and decrease burnout.

IMPLICATIONS FOR FUTURE RESEARCH:

• There needs to be further research on testing what caregiver traits are potential protective factors. Traits such as spirituality, physical health, level of relationship and positive outlook on life would be interesting to see how much these factors could contribute to caregiver’s resilience.

• Further evidence-based research should be done on interventions for caregivers that implement more occupational based strategies. Although, there is a large amount of data collected on the benefits of psychosocial therapy interventions for caregivers; it would be interesting to further investigate what kind of occupational intervention that focus more on activities and environments which support caregivers and patients.

REFERENCES


