Supporting People with Dementia and Family Carers in Transition to Nursing Home: A Systematic Review

Background
During the transition of people with dementia from home to nursing home, family carers are at increased risk of becoming burdened, stressed, having sleep disturbances, depression and other health complications [1]. From the carers’ point of view, problems become apparent due to being unprepared for the transition period, having limited support, being uninformined about care alternatives or financial options, and due to a lack of knowledge about dementia [2]. The transition from their home into a nursing home is an experience for people with dementia as well, representing loss of their home, neighborhood and time with family and friends; behavioral and neuropsychiatric symptoms often increase [3].

Methods
A systematic review was carried out [4] according to the Cochrane Handbook for Intervention Reviews V.5.1.0 [5].

Search strategy
• MEDLINE (via PubMed), CENTRAL, PsycINFO, CINAHL, Osteeken, and PEDro (Inception – July 2015), the Specialised Register of the Cochrane Dementia and Cognitive Improvement Group (ALDIS) and Google Scholar.
• Backward citation tracking.

Inclusion criteria
• Study types: Randomized controlled trials (RCTs), cluster-randomized controlled trials (cRCTs) and clinical controlled trials (CCTs).
• Types of participants: People with mild to severe dementia and family carers of people with dementia (any type of relationship).
• Types of interventions: Targeting people with dementia or their family carers with the objective of offering support during the transition.
• Types of comparator(s) and outcome measures: Usual care and all types of outcomes.
• Language: German or English.

Study selection and data extraction
Screening, selection and data extraction were performed independently by two researchers.

Quality appraisal
The Cochrane Risk of Bias tool [5] was used. The UK MRC framework [6] guided the assessment of the development, feasibility testing, evaluation and implementation of interventions.

Data synthesis
A narrative synthesis was performed because the studies were too heterogeneous in terms of design, methods, interventions and outcome measures.

Results

Objective 1: Description of interventions
• 5 studies (all from USA) described interventions supporting family carers
• None of the studies targeted people with dementia
• Characteristics of studies and interventions are displayed in Table 1.

Objective 2: Evaluation of effects of interventions
Statistically significant improvement in outcomes for the intervention for depressive symptoms of carers (p<0.05) compared to the control group that continued up to the 3-year follow-up.

Gaugler et al., 2008, 2011
Significant decrease in overall negative reactions to behavior problems over a 12-months period (p<0.01) compared with control group. No effect on frequency of behavior problems, role overload or role capability.

Gaugler et al., 2015
Reduction of emotional distress and role overload (p<0.05) at 8-months follow-up compared with control group. No significant differences were found for stress, depressive symptoms and carers adaptation to placement (p<0.10) (due to the small sample size).

Davis et al., 2011
Significant reduction in carers’ feelings of guilt and positive interactions with staff (p<0.05) compared to the control group after post-intervention measurement. No effect regarding depression, burden, facility satisfaction, resource use.

Paun et al., 2015
Significant improvement in carers’ heart-felt sadness and longing at three months (p<0.027), a significant drop in their guilt at the six-month (p<0.029) follow-up. Significant effects on burden, heart-felt sadness and longing, worry and isolation at the six-month.

Table 1 Characteristics of included studies (n = 5)

<table>
<thead>
<tr>
<th>Authors, year</th>
<th>Sample size</th>
<th>Sample design</th>
<th>Intervention strategy</th>
<th>Comparison</th>
<th>Outcomes</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mittelman et al., 2004</td>
<td>n=406</td>
<td>RCT</td>
<td>Individual and family counseling program, intervention program</td>
<td>Usual care with support</td>
<td>Depression, depressive symptoms</td>
<td>7 months</td>
</tr>
<tr>
<td>Gaugler et al., 2016</td>
<td>n=227</td>
<td>RCT</td>
<td>Individual and family psycho-counseling, support, intervention</td>
<td>Usual care</td>
<td>Support resources, stress</td>
<td>18 months</td>
</tr>
<tr>
<td>Gaugler et al., 2016</td>
<td>n=227</td>
<td>RCT</td>
<td>Psychosocial Intervention program for family carers and other family members</td>
<td>Usual care</td>
<td>Stress, depressive symptoms, adaptation to placement</td>
<td>8 months</td>
</tr>
<tr>
<td>Davis et al., 2011</td>
<td>n=25</td>
<td>RCT</td>
<td>Psychosocial support program</td>
<td>Usual care</td>
<td>Feelings of guilt, depression, burden, burden with staff, satisfaction, resource use (secondary outcomes: visiting frequency, quality of life, social support, negative reactions to care)</td>
<td>Post-intervention measurement</td>
</tr>
<tr>
<td>Paun et al., 2015</td>
<td>n=35</td>
<td>RCT</td>
<td>Group based psychosocial intervention program</td>
<td>Usual care</td>
<td>Chronic grief (secondary outcomes: depression, knowledge, skills)</td>
<td>6 months</td>
</tr>
</tbody>
</table>

Conclusion
Evidence regarding effectiveness of interventions supporting family carers during the transition of a relative with dementia to a nursing home is insufficient; studies are prone to overestimation of intervention effects due to risk of bias.

No supporting intervention supporting people with dementia was identified.
Careful development and evaluation of complex psychosocial interventions and well-designed RCTs with larger sample and rigorous methodology are warranted. Reporting on feasibility and implementation process is lacking but is crucial for evaluating transferability across settings and should be part of upcoming studies.

References

Included Studies
- Paun, E., et al., 2015.

Contact
Christian Müller
Email: astrid.stephan@medizin.uni-halle.de