Effectiveness of psychosocial interventions on the psychological health and wellbeing of family carers of people with dementia following residential care placement: a systematic review protocol

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Review question/objective: The objective of this review is to identify, appraise and synthesize existing evidence regarding the effectiveness of psychosocial interventions on the psychological health and emotional wellbeing of family carers of people with dementia who have moved into residential care. More specifically, the objectives are to determine the effectiveness of psychosocial interventions on any of these family carer outcomes after placement in residential care: burden, anxiety, stress, depression, guilt, grief and loss, quality of life and satisfaction with the care of the person with dementia.

Keywords Dementia; family carer; psychosocial interventions; residential care

Background

Dementia, characterized by progressive and irreversible cognitive and functional decline, is a leading cause of disability and dependence in older people worldwide.¹ In 2015, it was estimated that the number of people living with dementia globally was 46.8 million; this figure is predicted to reach 131.5 million by 2050.² Although most people with dementia and their families prefer that they remain living at home for as long as possible,³ research suggests that in high-income countries, between 60% and 90% will permanently move into residential care.⁴⁻⁶ Reasons for placement include the increasing impacts of care experienced by family carers, carer ill-health, increased behavioral and psychological symptoms experienced by the person with dementia, declining cognition and function of the person with dementia, increased frailty and falls, or an acute event such as hospitalization or severe illness.⁵⁻⁷

It is recognized that the decision to place a relative with dementia into long-term care, and the transition from caring at home to residential placement, is a difficult and stressful time for many family carers.⁸⁻¹⁰ Studies have shown that carers experience a mixture of emotions such as stress, guilt, grief, loneliness and loss, as well as relief, during this period.⁸⁻¹¹ The evidence is less clear on how family carers are affected following residential care placement. While some studies report that carer strain, burden and depression may be alleviated within 12 months of residential placement,¹²⁻¹⁵ research also indicates that psychological and emotional distress does not decrease for all carers. For example, while Gaugler et al.¹⁵ report overall clinically significant reductions in carer burden and depression following the institutionalization of the person with dementia, subsets of carers were found to be at continued risk of distress: wives and daughters were most likely to experience persistent burden, and husbands were more likely to experience depression.¹⁵ Time spent visiting the care home, loss of or change in the caregiving role, lack of satisfaction with the care provided, increasing cognitive and functional decline of the resident, and poor communication and conflict with staff or other family members have all been associated with continued carer burden and stress.⁸⁻¹⁰,¹⁶⁻¹⁸

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For spousal carers, feelings of grief and loss have been reported to be at their highest once the person with dementia has moved into residential care.\textsuperscript{19-23} A systematic review of grief reactions in dementia carers found that anticipatory grief (i.e. grief before the death of the family member) was greatest in the moderate-to-severe stages of dementia, in spouse carers and when the person with dementia is institutionalized.\textsuperscript{24} Furthermore, research suggests that anticipatory grief, which can occur in 47–71% of carers of people with dementia,\textsuperscript{24} is a significant predictor of carer depression, especially in the later stages of the disease.\textsuperscript{25,26}

In response to these findings, a number of researchers have highlighted the need for effective interventions to support carers following residential care placement.\textsuperscript{8-11,27} Psychosocial interventions, defined as “interventions involving interaction between people to improve psychological and/or social functioning, including well-being and cognition, interpersonal relationships and everyday functional abilities,”\textsuperscript{28}(p.286) appear to be promising in this regard. Such interventions are primarily aimed at improving family carers’ psychological health, emotional and social wellbeing, rather than their knowledge of dementia and practical caring skills. A number of reviews of the effectiveness of multi-component psychosocial interventions (e.g. including psychosocial, psychoeducational and other components) to support carers of people with dementia living in the community have previously been undertaken.\textsuperscript{29-34} These have concluded that despite methodological differences between the studies, some psychosocial interventions can be effective in reducing carer psychological morbidity (e.g. stress, depression and burden) and improving carer psychological wellbeing within a community context.\textsuperscript{29-34} Fewer primary research studies have been conducted regarding psychosocial interventions delivered to carers once the person with dementia has moved into residential care,\textsuperscript{35-38} and evidence on the effectiveness of such interventions is yet to be appraised and synthesized. Studies identified in a scoping search have reported mixed results. Ducharme \textit{et al.}\textsuperscript{36} did not find that their intervention reduced psychological distress in adult daughter caregivers, although successful outcomes relating to competence dealing with the healthcare staff were described. Davis \textit{et al.}\textsuperscript{35} reported that telephone calls to carers addressing psychosocial issues and discussing support options resulted in reduced carer guilt and more positive interactions with staff compared with the control group, but there was no effect on carer burden or depression. A study by Schulz \textit{et al.}\textsuperscript{38} found no intervention effect on caregiver depression and burden or anxiety, although significant time effects were found on these outcomes, regardless of group assignment. However, Gaugler \textit{et al.}\textsuperscript{37} reported significant reductions in carer distress at four months and carer overload at eight months and non-significant reductions in stress and burden in the intervention group compared to controls.

To our knowledge, no systematic review of psychosocial interventions delivered to carers of people with dementia once their relative has moved into residential care has been undertaken; preliminary searches of JBI Database of Systematic Reviews and Implementation Reports, Cochrane Library of Systematic Reviews, DARE, MEDLINE, CINAHL and Embase found no existing review on this topic. A systematic review of interventions to support people with dementia and their informal caregivers during the transition from home care to nursing home care has been identified in PROSPERO\textsuperscript{39}; however, the proposed review differs in terms of the type (i.e. psychosocial), timing (i.e. following residential placement) and outcomes (e.g. anxiety, guilt, grief and loss) of interventions included. Such a review is important to identify whether psychosocial interventions are effective within this context and to determine the magnitude of effects on a number of carer outcomes to make recommendations for future research and practice.

\textbf{Inclusion criteria}

\textbf{Types of participants}

The current review will consider studies that include any family carers of people with dementia who have moved into residential or nursing or long-term care. For the purposes of this review, dementia will be defined as any type, stage or severity of dementia as reported in the studies, with or without a formal clinical diagnosis. Family carers will be defined as any family member involved in providing unpaid care, support or assistance for their relative with dementia. Family carers may be biologically related to the person with dementia (e.g. sister, brother, son, daughter etc.) or related by acquisition (spouse, partner, daughter-in-law, etc.). Only studies
for which family carer data can be extracted separately will be included. Residential care will be defined as any “long-term care facilities which provide supervision and assistance in activities of daily living with medical and nursing services when required” (PubMed MeSH term definition), such as nursing homes and residential care facilities. Studies in settings providing acute or short-term care such as hospital acute care wards or respite care will be excluded.

**Types of interventions**
The current review will consider studies that evaluate the effectiveness of any psychosocial intervention designed to improve the psychological health and emotional wellbeing of family carers of people with dementia who have moved into residential care, including but not limited to counseling, psychotherapy, cognitive behavioral therapy (CBT), information/education/training or any combination of these. Interventions may be delivered to individuals, families or groups by any mode of delivery (e.g. face-to-face, telephone or online), and for any duration and dose.

**Types of comparators**
Comparators include no intervention, other non-pharmacological intervention or standard/usual care.

**Outcomes**
The current review will consider studies that include any of the following family carer outcomes as measured by a validated measurement tool:
- Burden (e.g. Zarit Burden Scale; Caregiver’s Burden Scale)
- Anxiety (e.g. State Trait Anxiety Inventory)
- Stress (e.g. Perceived Stress Scale; Caregiver Distress Scale)
- Depression (e.g. Center for Epidemiological Studies Depression Scale; Beck Depression Inventory)
- Guilt (e.g. Caregiver Guilt Questionnaire for Nursing Home Placement)
- Grief and loss (e.g. Marwit-Meuser Caregiver Grief Inventory; Grief Experience Inventory)
- Quality of life (e.g. SF-36; Adult Carer QOL Questionnaire)
- Satisfaction with care of the person with dementia who has moved into residential care (e.g. Family Perception of Care Tool; Ohio Department of Aging Family Satisfaction Instrument).

**Types of studies**
The current review will consider experimental study designs including randomized controlled trials, non-randomized controlled trials, quasi-experimental studies and before and after studies for inclusion.

**Search strategy**
The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Third, the reference list of all identified reports and articles will be searched for additional studies. Studies published in the English language from 1990 to the present will be considered for inclusion in this review. MEDLINE trend indicates that there are very few studies of psychosocial interventions in the dementia field prior to 1990.

The databases to be searched include: PubMed, CINAHL, Embase, AgeInfo, PsycINFO, ISI Web of Science, Cochrane CENTRAL, Current Controlled Trials, clinicaltrials.gov and NHS Research Register.

The search for unpublished studies will include: OpenSIGLE, PsycEXTRA, Mednar, New York Academy of Medicine Library Gray Literature Report, ProQuest Dissertations and Theses.

Initial keywords to be used will be:
- Condition: (dementia OR “Alzheimer’s disease”) AND
- Population: (family OR informal OR spous*) AND (care* OR caregiv*) AND
- Intervention: (psychosocial OR psychological OR psychotherap* OR “cognitive behavi?ral therapy” OR CBT OR counsel?ing) AND (intervention* OR therap* OR support OR treatment OR training OR education*) AND
- Setting: (“residential care” OR “residential aged care” OR “nursing home” OR “long term care” OR “institutional care” OR “care facilities for the elderly” OR “permanent care”) AND
- Language: English language
Assessment of methodological quality

Papers selected for full-text retrieval will first be screened for congruence with the review’s inclusion criteria; studies that meet the inclusion criteria will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI). Any disagreements that arise between the reviewers will be resolved through adjudication by the third reviewer. The JBI-MAStARI instrument assesses the risk of bias across 10 quality criteria for experimental studies (Appendix I).

Data extraction

Quantitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-MAStARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. Primary authors will be contacted if necessary to clarify any ambiguous or missing data.

Data synthesis

Quantitative data will, where possible, be pooled in statistical meta-analysis using Review Manager (RevMan; Computer Program, version 5.3 [The Nordic Cochrane Centre, The Cochrane Collaboration, Copenhagen]). Effect sizes expressed as odds ratio (for categorical data) and weighted mean differences (for continuous data) and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard chi-square and I² tests. Where statistical pooling is not possible, the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate.

Acknowledgements

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References

3. Alzheimer’s Australia. The most difficult decision: dementia and the move into residential aged care. Alzheimer’s Australia NSW; 2012.


Appendix I: Appraisal instruments

**MAStARI appraisal instrument**

**JBI Critical Appraisal Checklist for Randomised Control / Pseudo-randomised Trial**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>1. Was the assignment to treatment groups truly random?</td>
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<td>2. Were participants blinded to treatment allocation?</td>
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<td>3. Was allocation to treatment groups concealed from the allocator?</td>
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<td>4. Were the outcomes of people who withdrew described and included in the analysis?</td>
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<td>5. Were those assessing outcomes blind to the treatment allocation?</td>
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<td>6. Were the control and treatment groups comparable at entry?</td>
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<td>7. Were groups treated identically other than for the named interventions</td>
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<td>8. Were outcomes measured in the same way for all groups?</td>
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<td>9. Were outcomes measured in a reliable way?</td>
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<td>10. Was appropriate statistical analysis used?</td>
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Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_________________________________________________________

_________________________________________________________
Appendix II: Data extraction instruments

**MAStARI data extraction instrument**

**JBI Data Extraction Form for Experimental / Observational Studies**

<table>
<thead>
<tr>
<th>Study Method</th>
<th>RCT</th>
<th>Quasi-RCT</th>
<th>Longitudinal</th>
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<td>Observational</td>
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<td>Other</td>
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**Participants**

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<th>Population</th>
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<th>Group A</th>
<th>Group B</th>
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**Interventions**

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<th>Intervention B</th>
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**Authors Conclusions:**

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**Reviewers Conclusions:**

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### Study results

#### Dichotomous data

<table>
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<th>Outcome</th>
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<th>Intervention ( ) number / total number</th>
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#### Continuous data

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<tr>
<th>Outcome</th>
<th>Intervention ( ) number / total number</th>
<th>Intervention ( ) number / total number</th>
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