The effectiveness of psychosocial interventions focused on helping family carers of people with dementia as they experience grief during the dementia trajectory and in bereavement: a systematic review protocol

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Review objective
The objective is to examine the existing evidence regarding the effectiveness of psychosocial interventions to assist grief pre and post bereavement for family carers of people with dementia residing in the community or in a health or social care facility.

Review question
What psychosocial interventions for family carers of people with dementia are most effective in reducing:

- anticipatory grief;
- post-death grief (bereavement); and
- complicated grief?

Background
Dementia is a syndrome characterized by disturbances of higher cortical functions including memory, thinking, orientation, comprehension, learning capacity, language and judgment. Cognitive function impairments are frequently accompanied by deterioration in emotional control, social behavior or motivation.\textsuperscript{1} The syndrome occurs in more than 100 diseases of which the most prevalent include
Alzheimer’s disease, vascular dementia, mixed dementia, Fronto Temporal Lobar Degeneration (FLTD) and dementia with Lewy Bodies. Dementia usually becomes apparent in people in their late 70s or older, has a gradual onset, is progressive and irreversible. Early onset dementia has been described and is characterized by onset before the age of 65 and has a rapid, deteriorating course. The diagnosis is uncommon, difficult and often delayed. Further, it is not known whether the impact on family carers differs from those of carers of later onset dementia. The carer’s grief may be related to additional losses such as loss of income and the status associated with being a family member of someone in the workforce. These losses would not be specific to dementia. Therefore, family carers of people with early onset dementia will not be included in this review. The median life span after a diagnosis of dementia in Australia is unclear, however it was reported as 5-8 years in Britain.

Dementia was the third leading cause of death in Australia in 2010 accounting for 6% of all deaths, which was an increase 2.4 times that of 2001. There were an estimated 298,000 Australians living with dementia in 2011 and they were being assisted by approximately 200,000 informal carers in the community.

It is projected that there will be approximately 400,000 Australians living with dementia by 2020 and 900,000 by 2050. The estimates from 2011 indicated that two thirds of people living with dementia in the community had informal carers. With the predicted rise in the number of people living with dementia and the non-institutionalization policies encouraging residence in private dwellings, it is not unreasonable to expect a similar rise in the number of informal carers.

Informal carers are most commonly family members; spouses, adult children or a sibling, however neighbors and friends also help with personal care, transport, housework and other support for the person living with dementia on an unpaid basis. Further, 60% of carers of people living with dementia take on the role as they believe it is a family responsibility. As such, the term ‘family carer’ will be used throughout this review and is defined as a family member or friend who provides unpaid personal care, support and assistance. Family carers assist the person living with dementia both while living in the community and in a health or social care facility such as a hospital, retirement village or nursing home.

Family carers of people living with dementia provide care for an average of five years during which time care demands increase. Carers’ roles include assisting with activities of daily living, such as self care and mobility, health care, communication, household chores, transport, meal preparation, property maintenance and cognitive and emotional tasks. 81% of family carers of people living with dementia in the community have reported spending more than 40 hours a week in the caring role. As a consequence of this undertaking, carers’ experience long-term mental and physical health effects.

8 The effects include lack of energy, sleep deprivation, stress related illnesses, depression, anxiety, stress, anger, guilt and grief.

Grief is a normal psychological reaction in response to a significant loss. Family carers of people living with dementia experience multiple losses. Initially they experience anticipatory grief or pre-death grief, which is grief for the loss of personhood and a sense of who they were from the family carer’s perspective; and loss of companionship, personal freedom and control. Grief also occurs from losses in the quality of the relationship, intimacy, memory, communication, social interaction, health status and opportunities to resolve issues from the past. Ambiguity of the future, anger, frustration and guilt are factors that contribute to carers’ anticipatory grief. This grief is likely to be
prolonged due to the progressive and prolonged duration of dementia.\(^{12}\) Anticipatory grief is exacerbated by the loss experienced when the person living with dementia is no longer able to remain at home and becomes a resident in an established care facility.\(^{12}\) Finally, family carers’ experience grief for the loss upon the death of the person with dementia or the bereavement. Whilst bereavement is a universal experience following a major loss, family carers’ grief can become complicated or prolonged when a person experiences cognitive, behavioural, and emotional distress causing impairment in social functioning and performance for more than 6 months following a bereavement.\(^{15}\) In recognition of the dysfunction caused by complicated grief, ‘Persistent Complex Bereavement Disorder’ was included in the Diagnostic and Statistical Manual of Mental Health Disorders 5\(^{th}\) edition (DSM-5) in 2013 as a condition that requires further study. Further, ‘Prolonged Grief Disorder’ has been proposed for inclusion in the next version of the International Statistical Classification of Diseases and Related Health Problems (ICD-11).\(^{15}\) Features of complicated grief may include Post Traumatic Stress Disorder (PTSD), depression, anxiety, suicidal thoughts and poor physical health\(^{10}\) but it is separate to these disorders and does not respond to standard interventions for each.\(^{15}\)

The prevalence, predictors and associations of grief in family carers of people with dementia before and after the death of the person with dementia were identified by authors of a systematic review following synthesis of results from 31 studies encompassing both quantitative and qualitative methods.\(^{10}\) Anticipatory grief was greatest in spouse carers, when the person living with dementia was in the moderate to severe stage of dementia and increased when the person living with dementia was moved to reside in a health or social care facility. The authors reported poor quality evidence relating to the prevalence of grief in family carers but the prevalence of anticipatory grief in carers was cited as 47-71\% and complicated grief following the death of the person with dementia was reported in 20\% of carers. Predictors of normal and complicated grief post death were reported as being a spouse carer and having depression before the death of the person with dementia. Although grief in carers can be expected, the authors recommended identifying carers at risk of distressing anticipatory and complicated grief and targeting interventions to reduce morbidity in family carers.\(^{10}\)

As family carers’ grief has been recognized and risk factors for distressing and complicated grief have been identified interventions have been developed and implemented to assist family carers manage normal grief and reduce complicated grief.\(^{8, 9, 16-18}\) Interventions such as Easing the Way,\(^{17}\) Canadian Hospice Palliative Care Association model,\(^{16}\) The 3-A Caregiver Grief Intervention Model,\(^{8}\) and The Chronic Grief Management Intervention\(^{8}\) have all been published with the aims of relieving grief either pre or post-death or both.

Many systematic reviews have been published that report synthesized findings of the effectiveness of interventions for carers of people living with dementia.\(^{19-22}\) The outcomes reported include the effectiveness on carers’ depression,\(^{19-22}\) anxiety,\(^{18, 22}\) burden,\(^{19-22}\) quality of life,\(^{19, 21}\) self-efficacy,\(^{19, 20}\) satisfaction,\(^{19}\) social support\(^{19}\) stress,\(^{22}\) coping\(^{22}\) and carer wellbeing.\(^{20, 21}\) In addition, systematic reviews have reported the effectiveness of interventions on people living with dementia including rates of hospitalization, length of hospital stay and costs;\(^{21, 23}\) the reliability, validity and feasibility of instruments used for screening carer burden\(^{24}\) and family involvement in decision making for people living with dementia.\(^{25}\) Several protocols are registered in PROSPERO\(^{26-30}\) and Joanna Briggs Institute Library.\(^{31, 32}\) However, none of them have examined the effect of psychosocial interventions on family carers’ grief, loss or bereavement. With the expected number of family carers of people
living with dementia rising and recognition of the effects of grief on family carers, it is timely to synthesize the data on the effectiveness and association of psychosocial interventions on grief, loss and bereavement in family carers of people with dementia to provide the evidence to inform practice in this area.

**Keywords**

List each keyword separated with a semi colon and space

Dementia; carer; family carer; grief; anticipatory grief; prolonged grief; interventions; bereavement; loss

**Inclusion criteria**

**Types of participants**

This review will consider studies that include family carers of older persons (>65 years) with dementia. There are no age limits on participants and family carers includes spouses, adult children, siblings, friends and neighbors who provide unpaid personal care, support and assistance. Studies that include both paid and unpaid carers will be excluded unless the family carer data can be extracted separately. The definition of dementia will not be restricted to any specific type, stage or degree of severity however, studies of family carers of people living with early onset dementia will be excluded and papers that focus only on mild cognitive impairment without specifying the main focus on dementia will be excluded. Studies will be included regardless of whether a clinical diagnosis was reported however, studies of people who have a dual diagnosis will be excluded.

**Types of interventions**

This review will consider studies that evaluate psychosocial interventions in health and social care facilities and community settings designed to assist family carers adjust to grief, loss and bereavement both during the dementia trajectory and/or following death. Psychosocial interventions are defined as any intervention that emphasizes psychological or social factors rather than biological factors and will include, but not be limited to: support groups, counselling, models of care, self-care or self-management interventions, educational programs, workshops, telehealth and on-line support. Studies that report the effectiveness of drugs or other medical interventions will not be included.

**Comparison**

Comparators may include, but not be limited to: no treatment as a control, standard care or treatment as usual or an alternative intervention. Comparisons between different modes of delivery (online versus telephone delivery); comparators between different frequency or duration of interventions will be included. Papers that report correlates of grief but are not reporting the effectiveness of an intervention to reduce grief will be excluded.

**Types of outcomes**

This review will consider studies that report an outcome of grief in family carers. It will include, but not be limited to: anticipatory grief, grief, complicated grief, complex grief, prolonged grief disorder, loss and bereavement measured with validated instruments such as Marwit-Meuser Caregiver Grief Inventory (MM-CGI) and short form (MM-CGI-SF); Prolonged Grief Disorder-12 and 13 (PGD-12, PGD-13); Bereavement Risk Assessment Tool (BRAT); Bereavement Risk Index (BRI); Bereavement Experience Questionnaire-24 (BEQ-24); Core Bereavement Items (CBI); Grief Evaluation Measure
(GEM); Grief Experience Questionnaire (CEQ); Hogan Grief Reaction Checklist (HGRC); Inventory of Traumatic Grief (ITG); Revised Grief Experience Inventory (R-GEI); Texas Revised Inventory of Grief (TRIG); Two-Track Bereavement Questionnaire (TTBQ and TTBQ-CG30); Brief Grief Questionnaire (BGQ); Inventory of Complicated Grief (ICG); Inventory of Complicated Grief –Revised (ICG-R). Studies that report grief in family carers as a secondary outcome will be included.

**Types of studies**

The review will consider both experimental and epidemiological study designs including randomized controlled trials, non-randomized controlled trials, quasi-experimental studies, before and after studies, prospective and retrospective cohort studies, case control studies and analytical cross sectional studies for inclusion. The review will also consider descriptive epidemiological study designs including case series, individual case reports and descriptive cross sectional 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 (Ovid) and CINAHL Plus with full text (EBSCO) 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 article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English in or after 1995 will be considered for inclusion in this review. Recognition of complicated grief as a separate entity to depression and anxiety occurred and an early definition was published in 1995\(^34, 35\) thus, psychosocial interventions to address grief would not have occurred before this date.

The databases to be searched include:

CINAHL Plus, MEDLINE, EMBASE, Scopus, PsycINFO, Science Direct, Scopus, Web of Science

The search for unpublished studies will include:

ProQuest Dissertation and Theses, Google Scholar, CareSearch, NHMRC, Dementia Collaborative Research Centre and Resources for Enhancing Alzheimer’s Caregiver Health (REACH).

Initial keywords to be used will be:

Dementia: dementia OR vascular dementia OR mixed dementia OR Lewy Body OR frontal lobe OR Alzheimer*. Carer: carer OR spouse OR family caregivers OR caregiver

Phenomena of interest: caregiving grief OR anticipatory grief OR complicated grief OR prolonged grief OR chronic grief OR maladaptive grief OR palliative OR palliation OR mental health OR caregiver burden

Interventions: blended model OR Caregiver Grief Intervention Model OR Dementia Caregiver Grief Model OR Easing the Way OR model of grief care OR intervention* OR program*, person-centered care, support group OR counseling OR self-help group OR widow to widow program OR bereavement service OR Instrumental Activities of Daily Living OR case management OR social support

Study type: Quantitative OR quantitative study OR randomized controlled trial OR non-randomized
controlled trial OR experimental OR quasi-experimental OR observational study OR case-control OR cohort OR descriptive OR case series OR cross sectional.

**Assessment of methodological quality**

Papers selected for retrieval 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) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

**Data extraction**

Quantitative data will be extracted from papers included in the review by two independent reviewers using the standardized data extraction tool from JBI-MAStARI (Appendix II). Where data is unreported, aggregated in a form unsuitable for extraction or unclear, all efforts will be made to contact the authors to provide the raw data or clarify results. The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

**Data synthesis**

Quantitative data will, where possible, be pooled in statistical meta-analysis using JBI-MAStARI. All results will be subject to double data entry. Effect sizes expressed as odds ratio (for categorical or binary data), weighted mean differences (for continuous data) and relative risk for cohort studies and their 95% confidence intervals will be calculated for analysis. A random effects model will be used as appropriate. Heterogeneity will be assessed statistically using the standard Chi-square and also explored using subgroup analyses based on the different study designs included in this review. 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.

**Conflicts of interest**

No conflicts of interest to declare

**Acknowledgements**

This review is funded by the Dementia Collaborative Research Centre: Consumers and Carers.
References


31. Gallego CF, Andres I. Effectiveness of the interventions, of support and help by health professionals, on principal caregivers of patients with cancer and/or the most frequent types of dementia: a systematic review. JBI Library of Systematic Reviews. 2006:1-12.

32. Petriwskyj A. Interventions to build resilience in family carers of people living with dementia: a comprehensive systematic review. JBI Registered Systematic Reviews. 2014.


Appendix I: Appraisal instruments

MAStARI appraisal instrument

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

Reviewer: ___________________________ Date: ___________________________

Author: ___________________________ Year: ___________ Record Number: ___________

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
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<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)

__________________________________________________________________________

__________________________________________________________________________
# JBI Critical Appraisal Checklist for Descriptive / Case Series

**Reviewer**  
**Date**

**Author**  
**Year**  
**Record Number**

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<tr>
<td>1.</td>
<td>Was study based on a random or pseudo-random sample?</td>
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<td>Were the criteria for inclusion in the sample clearly defined?</td>
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<td>3.</td>
<td>Were confounding factors identified and strategies to deal with them stated?</td>
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<td>Were outcomes assessed using objective criteria?</td>
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<td>If comparisons are being made, was there sufficient descriptions of the groups?</td>
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<td>6.</td>
<td>Was follow up carried out over a sufficient time period?</td>
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<td>7.</td>
<td>Were the outcomes of people who withdrew described and included in the analysis?</td>
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<td>8.</td>
<td>Were outcomes measured in a reliable way?</td>
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<td>9.</td>
<td>Was appropriate statistical analysis used?</td>
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**Overall appraisal:**  
- Include [ ]
- Exclude [ ]
- Seek further info [ ]

**Comments (Including reason for exclusion)**

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Created by XMLmind XSL-FO Converter.
JBI Critical Appraisal Checklist for Comparable
Cohort/ Case Control

Reviewer .......................... Date ........................................

Author .......................... Year .................... Record Number ...........

1. Is sample representative of patients in the population as a whole?  Yes  No  Unclear  Not Applicable
2. Are the patients at a similar point in the course of their condition/illness?  Yes  No  Unclear  Not Applicable
3. Has bias been minimised in relation to selection of cases and of controls?  Yes  No  Unclear  Not Applicable
4. Are confounding factors identified and strategies to deal with them stated?  Yes  No  Unclear  Not Applicable
5. Are outcomes assessed using objective criteria?  Yes  No  Unclear  Not Applicable
6. Was follow up carried out over a sufficient time period?  Yes  No  Unclear  Not Applicable
7. Were the outcomes of people who withdrew described and included in the analysis?  Yes  No  Unclear  Not Applicable
8. Were outcomes measured in a reliable way?  Yes  No  Unclear  Not Applicable
9. Was appropriate statistical analysis used?  Yes  No  Unclear  Not Applicable

Overall appraisal:  Include ☐  Exclude ☐  Seek further info. ☐

Comments (Including reason for exclusion)

________________________________________________________________________

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Appendix II: Data extraction instruments

MAStARI data extraction instrument

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

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<td>Journal</td>
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#### Study Method

- RCT
- Quasi-RCT
- Longitudinal
- Retrospective
- Observational
- Other

#### Participants

- Setting
- Population

#### Sample size

- Group A
- Group B

#### Interventions

- Intervention A
- Intervention B

#### Authors Conclusions:

- ...
- ...

#### Reviewers Conclusions:

- ...
- ...

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Created by XMLmind XSL-FO Converter.
**Study results**

**Dichotomous data**

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**Continuous data**

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Extraction of findings complete

Yes ☐

No ☐