Effectiveness of interventions to improve family-staff relationships in the care of people with dementia in residential aged care: a systematic review protocol

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Review question/objective

The objective of this review is to identify and appraise existing evidence regarding the effectiveness of interventions designed to enhance staff-family relationships for people with dementia living in residential aged care facilities.

More specifically, the objectives are to identify the effectiveness of constructive communication, cooperation programs, and practices or strategies to enhance family-staff relationships. The effectiveness of these interventions will be measured by comparing the intervention to no intervention, comparing one intervention with another, or comparing pre- and post-interventions.

Specifically the review question is: What are the most effective interventions for improving communication and cooperation to enhance family-staff relationships in residential aged care facilities?

Background

In our aging world, dementia is prevalent and is a serious health concern affecting approximately 35.6 million people worldwide. This figure is expected to increase two-fold by 2030 and three-fold by 2050. Although younger-onset dementia is increasingly recognized, dementia is most commonly a disease that affects the elderly. Among those aged 65 to 85, the prevalence of dementia increases exponentially, and doubles with every five-year increase in age.

Dementia is defined as a syndrome, commonly chronic or progressive in nature, and caused by a range of brain disorders that affect memory, thinking and the ability to perform activities of daily living. While the rate of progression and manifestation of decline differs, all cases of dementia share a similar trajectory of decline. The progressive decline in cognitive functions and ultimately physical function that
these people face affects not only the person with the disease but also their family caregivers and health care staff.\textsuperscript{5}

The manifestation of dementia presents unique and extreme challenges for the family caregiver.\textsuperscript{6} Generally it causes great physical, emotional and social strain because the caregiving process is long in duration, unfamiliar, unpredictable and ambiguous.\textsuperscript{5,7} In the later stages of dementia, many family caregivers relocate their relative to a residential aged care facility, most often when the burden of care outweighs the means of the caregiver.\textsuperscript{7,8} This is especially likely when the person with dementia ages, and has lower cognitive function increased limitations in activities in daily living and poorer self-related health.\textsuperscript{9} As a result, approximately 50% of all persons aged 65 years or over admitted into residential aged care facilities have dementia.\textsuperscript{10}

The relocation of a relative into a residential aged care facility can be complex and distressing for family caregivers.\textsuperscript{11,12} While relocation alleviates many issues for the family caregiver, it does not consequently reduce their stress.\textsuperscript{7} The stress experienced by the family caregivers who remain involved post-relocation often continues and may even worsen.\textsuperscript{7} This is because family caregivers are uncertain about how to transition from a direct caregiving role to a more indirect, supportive interpersonal role, and may be provided with little support from care staff in this regard.\textsuperscript{7,13} Although family caregivers experience a new form of stress post-relocation, family involvement in residential aged care settings has been shown to be beneficial to residents with dementia, their families and care staff.\textsuperscript{13,14}

Family involvement is widely acknowledged to provide the resident physical and emotional healing, optimal well-being, and the sustainment of quality of life.\textsuperscript{13,14} Family caregivers benefit from improved satisfaction with the facility and experiences of care, and greater well-being. Care staff benefit from enhanced job satisfaction and greater motivation to remain in their job. The key to these positive outcomes is effective communication and strong relationships between care staff and family caregivers.\textsuperscript{13}

Effective communication between care staff and family caregivers is crucial for residents with dementia.\textsuperscript{13} This is because residents with cognitive impairment may have difficulties articulating their needs, concerns and preferences effectively.\textsuperscript{13} Family caregivers rely on staff for information about their relative’s behavior in the residential aged care facility; however they themselves have in-depth information about the resident’s physical, psychosocial and emotional histories that are necessary for developing individualized care support plans.\textsuperscript{13} Family involvement can support care staff in reducing residents’ behavioral symptoms by assisting to identify social and emotional needs, or unmet medical needs.\textsuperscript{7,13,15} Ineffective communication from family caregivers in conveying information to care staff may be disruptive in the caregiving process, and may lead to disagreement regarding respective roles and approaches to caring for the resident.\textsuperscript{15} Consequently, family caregivers may withhold information that may support care staff and improve care. They may also be concerned about negative repercussions for the resident.\textsuperscript{13}

Care staff and family caregivers generally have differing needs and expectations. Care staff are usually in the position where they have to manage a relationship with the family, which is based on multiple roles.\textsuperscript{15} Perceptions of family caregivers by care staff include seeing them as colleagues, subordinates, or people who themselves may be in need of nursing care.\textsuperscript{15} These different perceptions lead to role ambiguity and result in separate approaches to the caregiving process.
Cohen et al. suggest in their study that family involvement can benefit people with dementia in residential aged care settings, their family carers and staff,\(^{14}\) however further research is required. The relationship between care staff and family caregivers is often challenging due to problems with communication, role ambiguity of both care staff and family carers, and differing approaches to caring for the resident. These problems highlight the need for interventions to constructively enhance the quality of family-staff relationships. For example, one intervention called Partners and Caregiving\(^{16}\) has been reported as being designed to increase cooperation and effective communication between staff and family. In this study, staff and family members were randomly subjected to treatment and control conditions. The treatment group received parallel training sessions on communication and conflict resolution techniques, followed by a joint meeting with the facility administrators. The results of the study demonstrated improved outcomes in the form of improved attitudes of staff and family members towards each other, less conflict between family and staff, and fewer intentions of staff to quit. Further research is vital in order to identify effective family-staff intervention studies that can provide directions for implementation in residential aged care facilities. Furthermore, it is equally important to identify interventions that are ineffective, so as to provide insights into potential pitfalls to avoid in order to improve staff and family members’ relationships and the provision of care to people living with dementia in the future.

Previous systematic reviews have focused on factors associated with constructive family-staff relationships in caring for older adults in the institutional setting\(^ {15,17,18}\) and the family's involvement in decision making for people with dementia in residential aged care facilities.\(^ {19}\) This review will however specifically investigate interventions for improving communication and cooperation that promote effective family-staff relationships when caring for people with dementia living in residential aged care facilities.

**Keywords**

Dementia; residential aged care; staff; family; intervention; systematic review

**Inclusion criteria**

**Types of participants**

This review will consider studies that include:

1. Family caregivers of people with dementia who are living in residential aged care facilities
2. People with dementia who are living in residential aged care facilities
3. Health care staff working in residential aged care facilities who are caring for people with dementia.

All other settings will be excluded.

**Types of interventions**

This review will consider studies that evaluate interventions (e.g. programs, practices and strategies) designed to enhance family-staff relationships when compared to usual care (i.e. no intervention), when compared to another intervention, or compared to pre- and post-intervention. Family members include anyone involved in the caregiving process of the person with dementia, e.g. a husband or daughter. There is no limit to the age, diagnosis or severity of dementia of the person with dementia. All types of interventions will be considered and there are no limits on the minimum duration or amount of sessions.
conducted. Participation will include both staff and family and the intervention can be delivered by anyone. Studies that compare one intervention against another will also be considered for inclusion. Examples of such interventions include, but are not limited to, family-staff education workshops on communication and cooperation, family-staff meetings, complaints resolution, information programs and case discussions.

**Types of outcomes**

This review will consider studies that include the following outcome measures:

1. **Staff outcomes** (e.g. burden, stress, satisfaction with facility, well-being, turnover, and quality and satisfaction with family-staff relationships, including communication and cooperation): staff outcomes may be measured by such instruments as the Caregiver Stress Inventory,\(^{20}\) Interpersonal Conflict Scale,\(^{21}\) Family Behavior Scale,\(^{22}\) and the Zarit Burden Interview.\(^{23}\)

2. **Family outcomes** (e.g. burden, stress, satisfaction with facility, well-being, and quality and satisfaction with family-staff relationships): family outcomes may be measured by such instruments as the Zarit Burden Interview,\(^{23}\) Family Perception of Care Tool,\(^{20}\) and Interpersonal Conflict Scale.\(^{21}\)

3. **Resident outcomes** (e.g. physical and emotional healing, well-being, and quality of life): resident outcomes may be measured by such instruments as the Cohen-Mansfield Agitation Inventory,\(^{24}\) Activities of Daily Living Scale,\(^{25}\) and Minimum Data Set Cognition Scale.\(^{26}\)

**Types of studies**

This review will consider both experimental and epidemiological study designs including randomized controlled trials, non-randomized controlled trials, quasi-experimental, before and after studies, prospective and retrospective cohort studies, case control studies, and analytical cross sectional studies for inclusion.

Descriptive epidemiological study designs, including case series, individual case reports and descriptive cross sectional studies, will also be considered 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 PubMed and CINAHL will be undertaken followed by an analysis of the words contained in the title and abstract, and of the index terms used to describe the 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 hand searched for additional studies. Only studies published in English will be considered for inclusion in this review due to limited translation resources. Studies published from 1990 to 2015 will be considered for inclusion in this review. The year 1990 was selected as it was during this time that dementia started gaining prominence.

Databases to be searched include PubMed, CINAHL, SCOPUS, Ageline, APAIS Health, Australian Family and Society Abstracts (FAMILY), Care Search, Cochrane Central Register of Controlled Trials (CENTRAL), EBSCO Health Sources, Embase and ISI Web of Science

The search for unpublished studies will include Mednar (excluding Google Scholar) and ProQuest Dissertations and Theses
Initial keywords used will be:

General: dementia, family-staff, relationships, family carers, Intervention* and residential aged care.

Setting: aged care facility, aged care home, care home, home for the aged, long-term care, nursing home, residential aged care, residential care and residential facility.

Population: Older people, resident, care resident, older person, elder*, frail elderly, Alzheimer*, cognitive impairment, dementia*, social worker, staff, family-staff, nurses and health professional.

Outcomes: Stress, burden, turnover, satisfaction with facility, satisfaction with family-staff relationship, physical and emotional healing, well-being and quality of life.

**Assessment of methodological quality**

Quantitative 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 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 issues relating to ambiguous or missing data.

**Data synthesis**

Quantitative papers 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 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 also explored using subgroup analyses based on the different quantitative 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**

The authors declare that there are no conflicts of interest.

**Acknowledgements**

This review is to contribute towards the completion of a Doctor of Philosophy (PhD) for MyNhi Nguyen.
References


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>
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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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<tr>
<td>4. Were the outcomes of people who withdrew described and included in the analysis?</td>
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<tr>
<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

<table>
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<tr>
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<tbody>
<tr>
<td>1. Was study based on a random or pseudo-random sample?</td>
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<td>2. Were the criteria for inclusion in the sample clearly defined?</td>
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<td>3. Were confounding factors identified and strategies to deal with them stated?</td>
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<td>4. Were outcomes assessed using objective criteria?</td>
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<td>5. If comparisons are being made, was there sufficient descriptions of the groups?</td>
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<td>6. Was follow up carried out over a sufficient time period?</td>
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<td>7. Were the outcomes of people who withdrew described and included in the analysis?</td>
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<td>9. 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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____________________________________________________________________
### JBI Critical Appraisal Checklist for Comparable Cohort/Case Control

**Reviewer**  
**Date**

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

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<td>1.</td>
<td>Is sample representative of patients in the population as a whole?</td>
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<td>2.</td>
<td>Are the patients at a similar point in the course of their condition/illness?</td>
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<td>3.</td>
<td>Has bias been minimised in relation to selection of cases and of controls?</td>
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<td>4.</td>
<td>Are confounding factors identified and strategies to deal with them stated?</td>
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<td>5.</td>
<td>Are outcomes assessed using objective criteria?</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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Appendix II: Data extraction instruments

MAStARI data extraction instrument

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<th>JBI Data Extraction Form for Experimental / Observational Studies</th>
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<td>Author _____________________________ Year _____________________</td>
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<tr>
<td>Journal ___________________________ Record Number _____________</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:
## Study results

### Dichotomous data

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### Continuous data

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