The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review protocol

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Review question/objective
The objective of this review is to identify the meaningfulness of participating in support groups for informal caregivers of older adults with dementia living in their own home.

More specifically, the review question is:
How do informal caregivers of older adults with dementia, living in urban and rural settings, perceive the meaningfulness of participating in support groups?

Background
Dementia is a major public health problem. Worldwide, an estimated 65.7 million people will suffer from Dementia in 2030.¹ Dementia mainly affects older people over 65 years and causes progressive, irreversible cognitive deterioration with disturbances in behavior, impaired judgment and disorientation, loss of memory, language and the ability to perform basic activities of daily living.² In addition, policy-makers in many Western countries have successfully encouraged older adults to stay in their own home in order to increase quality of life and thereby reducing primary health service costs.³ As the disabilities and care needs of the older adult with dementia increase over time, the informal caregivers play a key role in the delivery of this health care worldwide.⁴ Informal caregivers are defined as mainly family members, who provide unpaid care for a relative with a chronic disease such as dementia, predominantly in their own home.⁴,⁵ Gaugler et al., performed a randomized controlled trial with 406
caregivers of people with Alzheimer’s disease over a nine-and-a-half year period in New York. The study provides evidence that participation in support groups produces a meaningful improvement in the wellbeing of the informal caregiver, but a transition of the person with dementia to a nursing home may be the only way to alleviate emotional or psychological distress for some caregivers after providing many years of care at home.

Informal caregivers perform care-related tasks around-the-clock. Performing at-home care for older adults with dementia has many consequences for the caregiver. While the positive aspects of care should not be overlooked, for example fulfillment, companionship and that a caregiver who experiences satisfaction provides better care; care giving can also put a great strain on the health and wellbeing of carers. Taking on a care obligation might lead to feelings of a meaningless existence, burden, anxiety, stress and fatigue; all identified risk factors for premature death among informal caregivers. Informal caregivers are therefore considered to be in great need for support from the public health care system.

Current research shows that support groups are considered an especially effective and economical way to relieve informal caregiver’s stress and burden. Support groups are defined as supportive, rarely standardized interventions, which can be both professionally led and peer-led. The groups focus on building sympathetic relations among participants in order to discuss problems, successes and feelings regarding care giving. Education is not the primary focus. Support groups differ in content, process and structure and it is unclear which groups produce a meaningful and optimal outcome for the informal caregivers. Meaningfulness is defined as the beliefs, satisfaction, benefits and rewards the informal caregiver experiences in the role as caregiver, with all of its related activities such as participating in support groups. Questions have been raised about the use of support groups for informal caregivers. A study reports that support groups are beneficial, but that there are no significant improvements in the feelings of burden from the support group participants. Still, the extensive use of support groups does not correspond with the current scientific knowledge about them.

Informal caregivers in urban and rural settings experiences different stressors. In rural settings the informal caregivers might have a higher level of negative mental impact, a limited use of respite care and a higher participation rate in support groups. Whereas Informal caregivers in urban settings might have a higher level of social isolation, a higher use of respite care and limited participation in support groups. How help is provided by attending support groups remains unclear, according to a historical review. McKenzie et al., point out in a systematic review that some studies indicate that rural informal caregivers fair better than urban informal caregivers, while other studies indicate that there are no urban-rural differences, or that urban informal caregivers fair better than rural informal caregivers. Research has not yet been able to account for these proposed differences. A systematic review has claimed that research into the use of public health services by both informal caregivers and elderly people with dementia living in rural areas is an important subject that has not yet been sufficiently investigated by research.

The provision of support group services by the public health care system should be optimally tailored to meet the specific individual needs of the informal caregiver. Reasons for not participating in support groups may include unawareness of the provision of such services, difficulty in choosing between the different care services and that the services provided won’t meet their needs. One study has
indicated that in order to get informal caregivers to participate in support groups, the intervention must be seen by the informal caregivers as meaningful and a way to improve their quality of life. An initial search in the databases Pubmed, CINAHL, JBIConnect+, DARE, PROSPERO and PsychINFO indicated that no systematic review on this topic exists or is currently underway.

**Keywords**

Older adults, informal caregiver, dementia, support group, peer support

**Inclusion criteria**

**Types of participants**

This review will consider studies that include informal caregivers of older adults aged 65 years and older with dementia, regardless of the severity of the disease and the duration of care. The informal caregiver is mainly seen as a family member and care must be performed at home.

The review will not differentiate between studies involving subsets of informal caregivers (e.g. based on specific ethnicity, gender and/or specific morbidities of dementia among the affected elderly in the care of informal caregivers or other specific differentiations). Should the data synthesis and analysis indicate differing results associated with subsets of informal caregivers, these will be reported separately.

**Phenomena of interest**

This review will consider studies that investigate how the informal caregivers of older adults with dementia, living in urban or rural settings perceive the meaningfulness of participating in support groups.

The phenomenon of interest will consider studies that include informal caregivers, aged 18 years and older, who are caring for an older adult with dementia, aged 65 years and older, living in their own home.

The setting will be all locations where support groups for informal caregivers have been held and studied.

**Types of outcomes**

The outcomes of interest include, but are not restricted to the following:

1. Subjective accounts of the informal caregivers’ perceptions of the meaningfulness associated with participating in support groups
2. Beliefs, benefits, rewards and attitudes of the caregivers experiences as a participant in support groups and in the role as caregiver
3. The perception of informal caregivers participating in support groups as a way to release stress

**Types of studies**

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.
In the absence of research studies, other texts such as opinion papers and reports will be considered.
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 analysis of the text 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 lists of all identified reports and articles will be searched for additional studies. Studies published in English, German, Danish, Swedish and Norwegian will be considered for inclusion in this review. Databases will be searched from their inception to December, 2013.

The databases to be searched include:

PubMed, CINAHL, Embase, Web of Science, PsychINFO, SveMed+, Bibliotek.dk, Trip database and WorldCat.

Additional searching for published literature will include:

Hand searching reference lists and bibliographies of included articles and any relevant systematic reviews identified in the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports. Conducting an online search of databases and websites including:

www.alz.co.uk (Alzheimer’s Disease International)

www.alzheimer-europe.org (The European Alzheimer umbrella organization)

http://ec.europa.eu/health (The European Commission on Dementia)

www.videnscenterfordemens.dk (Danish Dementia Research Centre)

www.aldringoghelse.no (Ageing and Health, Norwegian Centre for Research, Education and Service Development)

www.demenscentrum.se (The Swedish Dementia Centre)

www.dementia.stir.ac.uk (University of Stirling)

www.zfg.uzh.ch (University of Zurich)

www.dimdi.de (DIMDI - Medical Knowledge Online)

www.dnb.de (The German National Library)

www.rcn.org.uk (Royal College of Nursing, Dementia Nursing Research Taskforce)

www.proquest.com (ProQuest Dissertations & Theses Database)

www.theses.com (Index to Theses)

Initial keywords to be used will be:

Older adults, informal caregiver, dementia, support group, peer support
Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological quality prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data collection

Data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

Conflicts of interest

None identified.

Acknowledgements

The authors would like to thank Academic Librarian Maria Viftrup Schneider, M.L.I.S. for a substantial contribution to the comprehensive literature search.
References


Appendix I: Appraisal instruments

QARI appraisal instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

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<th>Reviewer</th>
<th>Date</th>
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1. Is there congruity between the stated philosophical perspective and the research methodology? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
2. Is there congruity between the research methodology and the research question or objectives? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
3. Is there congruity between the research methodology and the methods used to collect data? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
4. Is there congruity between the research methodology and the representation and analysis of data? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
5. Is there congruity between the research methodology and the interpretation of results? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
6. Is there a statement locating the researcher culturally or theoretically? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
7. Is the influence of the researcher on the research, and vice versa, addressed? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
8. Are participants, and their voices, adequately represented? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? [ ] Yes [ ] No [ ] Unclear [ ] Not Applicable
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? [ ] 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

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer ____________________ Date ____________________

Author ____________________ Year ____________________

Journal ____________________ Record Number ____________________

Study Description

Methodology ____________________

Method ____________________

Phenomena of interest ____________________

Setting ____________________

Geographical ____________________

Cultural ____________________

Participants ____________________

Data analysis ____________________

Authors Conclusions ____________________

Comments ____________________

Complete Yes ☐ No ☐
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Extraction of findings complete

Yes ☐ No ☐