

Sigma Final Grant Report
November 25, 2018

Experiences and Perceptions of Spousal/Partner Caregivers of Community Dwelling People with
Dementia: A Qualitative Systematic Review

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information)

1. Summary of project aims

To synthesize the evidence regarding the experiences of unpaid spousal/partner caregivers of
community-dwelling adults with a dementia.

2. Theoretical/conceptual framework

The methodology for this review is the Joanna Briggs Institute approach to Qualitative
Systematic Reviews informed by the tenets of naturalistic inquiry, and pragmatism, a priori
theory is suspended, the researcher is the instrument, and realities are multiple

3. Methods, procedures and sampling

Following JBI methods we identified our topic area then our research question. The title of this
review was structured using the mnemonic (PICO) where P identifies the population (unpaid
caregivers of older adults with dementia), I the phenomenon of interest (experiences of
spousal/partner caregivers), C the context (community dwelling), and O the outcome which is
not stated in the qualitative systematic review question, since the work involves the synthesis and
aggregation of interpretive studies and does not involve predictive studies. The JBI protocol
subsequently calls for elaboration of the study inclusion criteria, search strategy, title and
abstract retrieval and review, full text review, assessment of methodological quality, data
extraction, and data synthesis.

Papers selected for retrieval were assessed by two independent reviewers for methodological
validity prior to inclusion in the review using standardized critical appraisal instruments from the
Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) critical
appraisal checklist. Following JBI protocol all reviews have a primary and a secondary JBI
trained reviewer. Both these reviewers review all papers retained and independently assess them.
The primary reviewer then verified for consensus. Conflicts were resolved through discussion, or
with a third reviewer.

One of the assumptions underlying this review was assuring trustworthiness of the findings
through transparency in describing the methods. Trustworthiness is comprised of the elements of
credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility
means that the processes used to carry out this review are made explicit and that the review team
reach consensus on the findings. The data extraction processes are described below including
allowance for the research team to review and reach consensus on the findings. Transferability
addresses the question as to whether or not the findings from this work can be applied in other
settings. This is assured by a thorough description of methods so that others reading the work

will be able to make decisions about the applicability of the work in their settings. Dependability is assured by demonstrating a second researcher following the same methods will obtain similar findings. In this review we allowed for this by having two JBI certified reviewers review all abstracts to decide on which manuscripts will be retained. This is further enhanced when the extracted data are subjected to the review team for scrutiny. Confirmability was established when there was general agreement among the research team that the findings generated were linked to the data and the knowledge generated was truly meaningful to unpaid caregivers of adults with a dementia.

4. Summary of findings

Nineteen studies were included in the review. Study designs included Phenomenology (8), Grounded Theory (5), Qualitative Description (4) Ethnography (1) and Narrative Inquiry (1). The total number of participants was 248, 164 women and 84 men. The overall quality of the studies was rated as moderate on the ConQual score, with dependability as moderate and credibility as high. One hundred and fifty five findings were aggregated into four categories and two synthesized findings. The categories identified were: Caregiver duties, need for information and resources, disappearance of a way of being, and consequences of caregiving. The two synthesized findings were the expectation to care in the midst of uncertainty and unpredictability, and the caregiver as hostage.

5. Recommendations/Implications

Implications for practice

Healthcare provider knowledge and awareness of the extent of role change for both caregivers and recipients and the associated emotions is essential. For example, spouses assuming the role of financial decision-maker for the first time, providing personal care, and attempting to manage aggression. These changes evoked emotions ranging from grief for some to empowerment for others.

Healthcare providers and spousal/partner caregivers need to have access to up-to-date knowledge and tools on all information and resources relevant to caregiving in dementia, including caregiver assessments (information about dementia, dementia management, how to access professional resources to assist with care, knowing when to ask for help).

Support for spousal/partner caregivers is of high importance. Support in the form of education on dementia management from healthcare providers; support in the provision of personal care to the person with dementia who is resisting; support in the form of respite to permit the caregiver personal time to conduct the business of the household; and social support to keep the caregiver connected to the community because time away from the home diminishes as care recipient demands rise.

Implications for policy

Healthcare providers and researchers need to come together to assist policy makers to understand how social structures render caregiving invisible and largely unpaid. Governments are relying on women's acceptance of the gendered nature of women's work and that many women will dutifully provide care as expected despite the personal cost. Caregiver benefits need to be in an amount sufficient to recognize the work of spousal/partners as legitimate and a major contribution to the healthcare system.

Support is necessary for learning new skills across gender lines such as cooking, housekeeping, managing finances and liaising with tradespeople. Public awareness campaigns about dementia, dementia caregiving, and the social structures that render caregiving invisible are essential to reduce stigma associated with dementia and to tangibly recognize the caregiver role. Such campaigns must also include what services and supports are available as well as options for addressing costs. Legitimate options for care no matter income are required for people with dementia and their spouses/partners. Spousal/partner caregivers need to be in a position of choice, not guilt or poverty in deciding to care for a person with dementia.

Implications for research

There is a need to conduct studies of the experiences of partner caregivers among the LGBTTQQAAP population. Further studies on the gendered nature of spousal/partner caregiving are recommended. Research related to the experiences of non-Caucasian spouses/partners, in particular among Indigenous peoples is recommended. Culturally informed, gender sensitive interventional research that evaluates what works best for which caregivers is essential.

6. Financial summary

7. Check for any unused funds

8. A 3-5 sentence testimonial on how receiving the grant assisted you in completing your research.

Anytime a researcher receives a grant it is extremely motivating and affirms that others see the value of the work. The grant from Sigma enabled the team to have the support of a research assistant to organize weekly team meetings, keep notes, trouble shoot using the JBI software and assist with title and abstract review, full text reviews and data extraction. All of this support enabled us to complete the report in the timeline outlined, and submit for peer review. We received editor and reviewer feedback from *The Joanna Briggs Institute of Systematic Reviews and Implementation Reports* in October indicating the report was accepted for publication pending minor revisions. Revisions were submitted November 18, 2018.

