

Carers' experiences when the person they have been caring for enters a residential aged care facility permanently: A systematic review

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Contents

ABSTRACT	i
DECLARATION	iv
ACKNOWLEDGMENTS.....	v
LIST OF TABLES.....	vi
LIST OF FIGURES.....	vii
ACRONYMS.....	viii
CHAPTER 1 BACKGROUND TO THE SYSTEMATIC REVIEW STUDY.....	1
1.1. INTRODUCTION	1
1.2. AGED CARE CONTEXT AND MOTIVATION FOR THE REVIEW.....	1
1.3. EVIDENCE-BASED HEALTHCARE AND SYSTEMATIC REVIEW.....	5
1.4. DEFINITIONS	11
1.5. SYSTEMATIC REVIEW OBJECTIVE.....	11
1.6. STRUCTURE OF THE DISSERTATION.....	12
CHAPTER 2 SYSTEMATIC REVIEW METHOD	13
2.1. INCLUSION CRITERIA	13
<i>2.1.1. Types of studies</i>	<i>13</i>
<i>2.1.2. Types of participants.....</i>	<i>13</i>
<i>2.1.3. Phenomenon of interest.....</i>	<i>13</i>
<i>2.1.4. Context.....</i>	<i>14</i>
2.2. SEARCH STRATEGY	14
2.3. ASSESSMENT OF METHODOLOGICAL QUALITY	15
2.4. DATA EXTRACTION AND SYNTHESIS METHOD.....	15
CHAPTER 3 RESULTS.....	18
3.1. DESCRIPTION OF STUDIES	18
<i>3.1.1. Search and study selection</i>	<i>18</i>
<i>3.1.2. Methodological quality.....</i>	<i>20</i>

3.1 3. Characteristics of included studies.....	24
3.2. SYNTHESIZED FINDINGS.....	31
3.2.1. Synthesized finding 1	31
3.2.2. Synthesized finding 2.....	38
3.2.3. Synthesized finding 3	41
CHAPTER 4 DISCUSSION	45
4.1. SUMMARY OF THE REVIEW FINDINGS AND THEIR SIGNIFICANCE	45
4.2. KNOWLEDGE GAPS.....	48
4.3. LIMITATIONS	48
4.4. RECOMMENDATIONS FOR PRACTICE	49
4.5. RECOMMENDATIONS FOR RESEARCH	50
4.6. CONCLUSION	51
CONFLICT OF INTEREST	51
REFERENCES	52
APPENDICES.....	57
Appendix I: Search Strategy.....	57
Appendix II: JBI QARI Critical Appraisal Checklist.....	61
Appendix III: JBI QARI Data Extraction Instrument.....	62
Appendix IV: Studies excluded at full text examination and critical appraisal with reasons	65
Appendix V: List of study findings.....	72

Abstract

Background

According to the literature, the experience for carer's when the person they have been caring for permanently enters a residential aged care facility, is emotional, complex and challenging. Experts have raised the importance of understanding the experience in order to support and implement policies and programs. The systematic review was motivated by this need to use the evidence base to inform effective and feasible interventions to support carers, and the absence of a systematic review synthesizing the qualitative evidence on how carers experience the transition.

Objectives

To identify and synthesize the evidence on the experiences of carers of older people when the person they had been providing care to is admitted permanently into a Residential Aged Care Facility (RACF) and draw recommendations from the synthesis of the evidence on these experiences to enhance understanding and inform practices aimed at supporting affected carers.

Inclusion criteria

Types of participants

All unpaid carers of people who had experienced the person they had been caring for at home being moved into a RACF permanently.

Phenomenon of interest

Experiences of the carer of the older person when the person they have been caring for at home is admitted into a RACF permanently.

Types of studies

The review considered qualitative studies, including but not limited to designs such as phenomenology, grounded theory, ethnography and action research.

Context

Very High Human Development Index countries were included as 'developed countries'.

Search strategy

A comprehensive search of the leading databases which are sources of qualitative

published and unpublished studies was conducted between 18 September 2013 and 10 November 2013. The search considered studies reported in English and published from database inception to 10 November 2013.

Methodological quality

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the appraisal tool in the Joanna Briggs Institute (JBI) Qualitative Assessment and Review Instrument (JBI QARI).

Data collection

Data were extracted from identified papers using the standardized data extraction tool from JBI QARI. The data extracted included descriptive details about the phenomena of interest, populations and study methods.

Data synthesis

The JBI meta-aggregative approach for synthesizing qualitative evidence was used. Research findings were pooled using JBI QARI. Study findings that were supported by the data in primary studies were organized into categories on the basis of similarity of meaning. These categories were then subjected to a meta-synthesis to produce a set of synthesized findings.

Results

Fourteen studies matched the inclusion criteria and were included in the review. From these 14 studies a total of 71 study findings about how carers experience the transition when the person they have been caring for is admitted permanently into a RACF were organized into seven categories. From the seven categories created on the basis of similarities of meaning, the following three synthesized findings describing the experience were produced:

- (i) Carers experience mixed feelings (including guilt, loss of control, failure and relief) when the person they have been caring for is admitted permanently into a RACF, which often occurs after a crisis. Carers seek validation about the decision and often display a need for support before during and after the move to RACF;
- (ii) Carers may experience the separation as sudden and unplanned, and feel that maintaining continuity in care after admission of the person they have been

caring for into the RACF is important for alleviating the loneliness and changed sense of identity they experience;

- (iii) Planning and building familiarity with the RACF prior to the move may help carers to minimize the experience of loss of control that is common when moving a person one has been caring for permanently into a RACF. This experience is made worse by those involved focusing on administrative issues and not being mindful of carers' psycho-social needs during the admission process.

Conclusions

The findings highlight the importance of interventions being implemented to provide support for carers prior to the person going into a RACF, at the decision making time, during the move and post-move. Carers experience mixed feelings and have difficulty coping with the separation and visit the RACF to maintain the relationship. Pre-planning prior to the move is important as the evidence suggests that when there is a sense of familiarity with the choice of RACF there is a more positive perception of the transition from the carers' perspectives. The findings call for health care professionals and RACF staff to assess the psychosocial needs of carers, and where feasible promote steps that enable the carers to continue to have a caring relationship after separation.

Implications for Practice

It is suggested that carers should be encouraged to plan for the placement early on and develop a sense of familiarity with RACF before the transition. Carers should be given specific information about the RACF prior to the older person being moved. Health care professionals should be mindful to consider carers' needs at the time of the transition and to facilitate strategies for a continuing relationship post-move.

Implications for Research

Additional high quality studies are required to develop a clearer understanding of support interventions and how they might interact and benefit the targeted carer population.

Keywords

Carers, older person, separation, experiences, residential aged care facility, qualitative.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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List of Tables

Table 1	Assessment of included study quality.....	22
Table 2	Key characteristics of included studies	28
Table 3	Summary of evidence credibility for all synthesized findings.....	31

List of Figures

Figure 1.	Systematic review as a component of evidence-based healthcare –The JBI model	7
Figure 2.	Flow diagram detailing search results, retrieval and selection of studies ..	19
Figure 3.	Meta-aggregative synthesis summary for synthesized finding 1: Carers' mixed feelings mixed feelings, crisis and need for support.....	36
Figure 4.	Meta-aggregative synthesis summary synthesized finding 2: Sudden separation and a desire for continued relationship.....	40
Figure 5.	Meta-aggregative synthesis summary for synthesized finding 3: Familiarity with a RACF and the impact of processes associated with the transition	44

Acronyms

ACAT	Aged Care Assessment Team
CASP	Critical Appraisal Skills Programme
CINAHL	Bibliographic database (nursing and allied health)
Embase	Bibliographic database (biomedicine)
EPPI	Evidence for Policy and Practice Information
EPPI - Centre	Evidence for Policy and Practice Information - Centre
F	Females
JBI	Joanna Briggs Institute
JBI CREMS	Joanna Briggs Institute Comprehensive Review Management System
JBI QARI	Joanna Briggs Institute Qualitative Assessment and Review Instrument
M	Males
MeSH	Medical Subject Headings used in MEDLINE database
MEDLINE	Bibliographic database (medicine)
Mednar	Public and subscription collection for medical researchers
OT Seeker	Database for Occupational Therapy Systematic Evaluation of Evidence
PICOS	Population, Interventions, Comparators, Outcomes and Study Designs
PRISMA	Preferred Method of Reporting Items for Systematic Reviews and Meta-analysis
ProQuest	Comprehensive collection of dissertations and theses
PsycINFO	Bibliographic database (psychology and psychiatry)
PubMed	Biomedical literature from MEDLINE
RACF	Residential Aged Care Facility
RCT	Randomised Controlled Trial
SDAC	Survey of Disability, Ageing & Careers
SF	Synthesized Findings
SCOPUS	Abstract and citation database of peer-reviewed literature