

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

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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published and unpublished studies was conducted between 18 September 2013 and 10 November 2013.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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Date:.....

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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

Chapter 1 – Background to the Systematic Review Study

1.1 Introduction

This thesis is comprised of an application of the Joanna Briggs Institute (JBI) systematic review methodology for reviewing qualitative evidence. It identifies and synthesizes the best available evidence to understand the experiences of carers on the permanent move of a care receiver into a Residential Aged Care Facility (RACF). The question it addresses is: What is it like for carers when the person they have been caring for is moved into a RACF permanently?

The JBI methodology for systematic review is rooted in the evidence based healthcare paradigm, which sees the purpose of systematic review not only as an academic pursuit, designed to contribute to knowledge, but also as a tool to inform practice and/or policy and thereby enhance health outcomes. The purpose of conducting the systematic review reported on in this thesis was to provide experiential evidence that may be translated into practice and used by health care professionals and aged care service providers to enhance carers' wellbeing throughout the transition of an older person to a RACF, particularly in the Australian aged care context.

This chapter describes the context of and motivation for the review. It begins by describing the Australian aged care context, the growing burden on unpaid carers to support the elderly and the need to develop effective evidence informed measures to support them. Section 1.3 describes the science of evidence synthesis in the context of evidence-based healthcare and introduces the JBI methodology for systematically reviewing qualitative evidence. Section 1.4 defines key terms used in the review. Section 1.5 presents the systematic review objective. Section 1.6 concludes the chapter by outlining the thesis structure.

1.2 Aged care context and motivation for the review

Australia has a growing aged population and the older population is increasing as a share

of the total population.¹ The Carers Strategic Plan (2012) indicates that there are an estimated 2.6 million carers in Australia who provide unpaid care and support to family members and friends living with a disability, mental illness, chronic condition, terminal illness, drug and alcohol issue or who are frail or aged.² Around 520,000 carers (25.4 percent) are estimated to be 65 years and older.³ The Survey of Disability, Ageing & Carers (SDAC) 2009 suggests that 620,000 carers were born outside of Australia, with 366,700 carers born in non-English speaking countries.⁴ Official estimates may under represent the number of carers in Australia, as many people view their caring as a normal part of life, of being a wife, husband, sibling, or even friend, and never think of themselves as carers or identify as carers.³

Caring may mean different things to different people, as carers are a diverse group of people whose needs are as diverse as those for whom they care.⁵ In Australia, the SDAC 2009 data indicate that approximately (76.7%) of primary carers care for immediate family members (parent, child or partner) and live in the same household as the person they care for.³ SDAC 2009 identifies almost half of the primary carers (44.7%) as providing care to their spouse or partner.³ Where the primary carer was 65 years or over, the gender balance shifted from predominantly female carers in the 25 to 64 year age group to a more even gender balance with 7% of men and 7.2% of women aged 65 years or over being the primary carers for their partner/spouse.³

Economically, carers make a strong contribution to society.³ For example in 2010 "Access Economics" estimated that the contribution of carers to the economy to be close to 1.32 billion hours of unpaid care each year.² Moreover, replacing this care with formal care services would cost \$40.9 billion per annum to the Australian economy.³ In Australia many primary carers are aged 65 or over and live in the same household as their care receiver.⁶ At times some people are under 65 years of age and may need to be admitted into a RACF themselves if deemed to have an age-related condition. In Australia Aboriginal and Torres Strait Islander people are deemed eligible for admission into a RACF at 50 years of age due to their shorter life expectancy and their poorer than average health outcomes.⁷ This is also relevant to indigenous persons internationally.

Given the important role that carers play in promoting the wellbeing of those they care for and the economic contribution made by carers to society, supporting carers, including those that have experienced moving an older person into a RACF permanently, is important. This is acknowledged in the aged care reform agenda in Australia.⁵ For example the Productivity Commission aged care reform report released in 2012 acknowledges the essential role that unpaid carers provide to support the lives of those they care for in the community and how imperative it is to ensure support is available to carers.⁸ The Australian Government recognizes the need to consider carers as partners with other care providers, as demonstrated in the "Carer Recognition Act, 2010".⁹ Also, as part of the Aged Care Reform agenda, "The Living Longer. Living Better - Supporting Carers" initiative has been developed.¹ This focuses on increasing access to and the flexibility of services that carers need, including a new home support program, and consumer-directed care packages, which aim to keep people being cared for in their homes longer into the future. Improvements are planned for providing increased funding for respite services, counselling support and establishing a regional network of carer support centres from July 2014 with funding expected to grow each year.¹

Although not all carers are elderly, the importance of designing and implementing effective measures of support for this group of carers is underlined by research suggesting that elderly carers are one of the most vulnerable groups in society, having amongst the poorest health and well-being indicators.

The systematic review on which this dissertation reports focuses on understanding the experiences of carers to inform best practice support for unpaid carers of elderly individuals at a particular stage in the care-giving/care-receiving relationship, this stage being the period of separation of the care-giver and the care-receiver and more specifically the experience of the carer when the person is admitted into a RACF permanently.

A preliminary search of a selection of electronic databases – JBI (Connect+), PsycINFO, OT Seeker, PubMed, Embase and Cochrane - revealed that there is a substantial volume of primary research based on qualitative research designs exploring how carers experience the residential care placement process and why family members cease care-giving at home. A qualitative primary study by Ryan and Scullian identified some of the factors leading family carers to place their older relatives into a RACF.¹⁰ This was

important as interviewed carers indicated that admission to a RACF was held off as long as possible but that the deteriorating health of the older relative and in some cases their own health, meant that there was no other option.¹⁰ Admission to a RACF usually followed a period of prolonged care at home and occurred at a time of crisis.¹⁰ Crisis is a term used in the studies to describe a point when people are not able to cope with the care of the person at home, with the care receiver being hospitalized and often admitted to a RACF from the hospital. Family carers complained that they were given inadequate support from health care professionals and often had no choice in the decision-making process.¹⁰ Carers often experienced ambiguous feelings about admitting their older relative into a RACF, and feelings of relief that the burden of care had been lifted were sharply contrasted with feelings of guilt that they could not continue with their “duty of care”. The findings in this study suggest that while many carers were relieved of the physical exhaustion surrounding care in the home, their emotional turmoil continued long after admission of the person into a RACF in Australia.¹⁰ Other qualitative studies involving carers and family care-givers have identified similar experiences of feeling unsupported, as well as reporting phases in the process of admission of a family member to a RACF ranging from making the decision, making the move, adjusting to the move and reorientation.^{11,12,13,14}

Whilst the preliminary literature identified some qualitative studies on the phenomenon of interest, no systematic review(s) with the objective of exploring the experiences of carers when the person they have been caring for at home is admitted permanently into a RACF was found. It is in this context that the value of this systematic review is that it provides evidence of how carers experience the move of the person they have been caring for to assist in informing practices in relation to supporting carers of the aged.

Internationally, populations are ageing and placing demands on countries. Countries included in this review have differing systems in place to care for their ageing citizens. For instance Korea is experiencing an ageing population much faster than other OECD countries.¹⁵ Korea in 2008 implemented a universal long term care insurance where a person’s needs are assessed at municipal level by an assessment committee of 15 persons based on a person’s physical and mental status irrespective of other financial status or family support and utilising a checklist with a maximum score of 100. A score of 55 and over deems an individual eligible for insured care.¹⁵ Whereas, in Sweden there is no general

guidance on the assessment of needs of the elderly in Sweden.¹⁶ Local authorities including county councils and municipalities assign a person to interview family members to determine the extent of support that the elderly person requires.¹⁶ Contrast this with the United States, where most of the aged care providers are publicly owned and managed as for-profit businesses, apart from the not-for-profit Evangelical Lutheran Good Samaritan Society.¹⁷ Similarly, Canada has private for-profit and not-for-profit facilities. The government may subsidize the facility and the elderly Canadians may pay for their care on a sliding scale based on annual income.¹⁷ In Australia aged care is designed that every Australian contributes as much as possible toward their cost of care depending on their individual income and assets and they are assessed by a federal funded Aged Care Assessment Team (ACAT).¹⁷ Within the United Kingdom there are also a range of for-profit and not-for-profit providers. The local authority conduct a care needs assessment to identify the help needed and carry out a means test to work out the contribution amount.¹⁸

Since the completion of the systematic review that this dissertation is based on a systematic review focussing on carers needs of people with dementia during the care transition period from care at home to institutionalised care has recently been published. It also focussed on the needs of informal care-givers during transition from home towards institutional care but only on carers of people with dementia. The review reported that the care-transition period be considered as a continuum due to similar needs and problems that were identified prior to and after admission to a RACF.¹⁹ The findings identified that carers of people with dementia experience emotional concerns, grief and shame about the decision, and have a need for knowledge and information and support.¹⁹ The findings are similar to the findings in the systematic review on which this dissertation reports.

1.3 Evidence-based health care and systematic review

Evidence-based health care has evolved over time. Archibald (Archie) Cochrane is known as one of the early pioneers of evidence-based medicine.²⁰ Evidence-based medicine may be defined as the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.^{20(p71)} The systematic review was introduced as a tool to promote evidence-based healthcare and improve health outcomes. The systematic review of several randomized trials has become the “gold standard” for judging the efficacy of a treatment and whether a treatment does more good

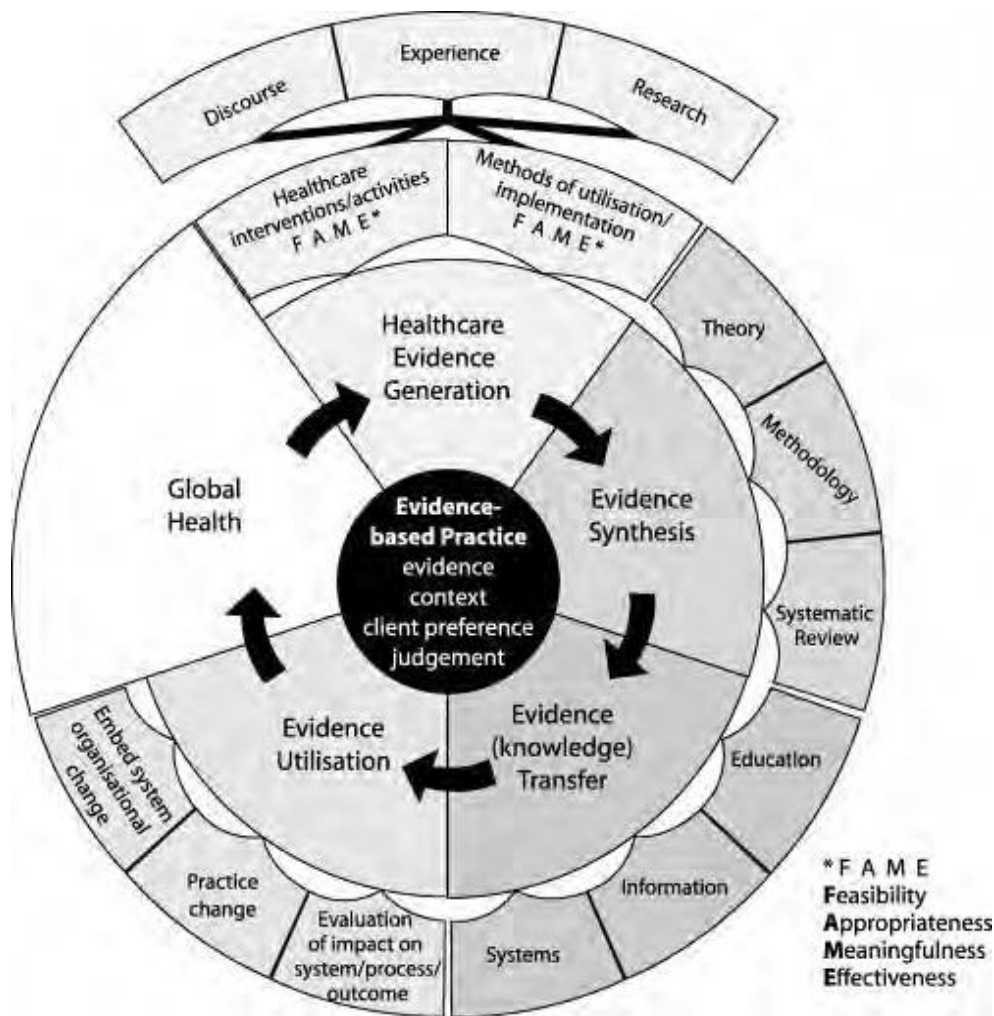
than harm.²⁰

Initially systematic review's focus was narrow, and covered synthesis of quantitative evidence to address questions about efficacy. Over time and informed by decision makers need to have questions beyond treatment efficacy answered to support evidence-based decision making, the scope of the systematic reviews has widely expanded. Now there are methods and tools to identify, appraise and synthesize diverse forms of evidence including qualitative evidence.²¹ The Cochrane Collaboration has been the leading player at the international level providing method guidance and tools for the conduct of systematic review of evidence to address questions about intervention efficacy.²² Various other organizations, including the JBI Centre for Reviews and Dissemination (CRD) and the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI) also offer guidance and tools.²³ The JBI has been at the fore-front of the development of rigorous methods for systematically reviewing qualitative evidence to promote evidence informed healthcare. The JBI's method for synthesizing qualitative evidence is the meta-aggregation approach.²² Qualitative meta-synthesis, including using the meta-aggregation method of JBI, involves re-interpretation of published findings, unlike secondary data analysis, which is based on primary data.²⁴ A strength of the meta-aggregation approach is that it does not elevate one particular qualitative study method above another, and enables, following critical appraisal, synthesis of findings from studies that use different qualitative methods.²⁵

The systematic review of literature on a particular condition, intervention or issue lies at the core of evidence-based healthcare.²⁶ In addition to consideration of evidence, of which systematic review is seen as the highest form, evidence-based healthcare is informed by clinical wisdom and patient preference. The JBI model of evidence-based healthcare captures this. Systematic reviews are transparent processes of secondary research analysis that aim to provide comprehensive and unbiased summaries of the evidence on a specific topic. They bring together multiple individual studies in a single document, providing the best evidence for clinical decision making.²³ Conducting a systematic review involves utilizing explicit and rigorous scientific processes, which aim to minimize risk of error and bias.²³ The systematic review process is more rigorous than the traditional method of a literature review where there may not be a comprehensive search strategy nor

the use of a critical appraisal tool.²⁷

The figure below presents the JBI model of evidence-based healthcare and shows how systematic review (one type of method of “evidence synthesis” referred to in diagram) is only one part of the process of translating research into improved health outcomes.²⁸



From: Pearson A, Wiechula R, Court A, Lockwood C. The Joanna Briggs Institute. Model of evidence-based health care. *International Journal of evidence-based healthcare*. 2005;3(8):207-215.

Figure 1: Systematic review as a component of evidence-based healthcare - The JBI model

Systematic review is a particular type of literature review that follows clearly defined steps of question definition, evidence identification, critical appraisal, and data synthesis to increase the validity of findings and recommendations. In a systematic review a rigorous and extensive search of the literature on a given topic is undertaken. The search findings are then assessed for their applicability to the topic and appraised using standardized tools to ensure that only the results of the highest quality research are included.²⁹ The systematic review process applied to qualitative evidence is described by the following eight steps, related to the JBI Model:

1.3.1 JBI Model qualitative evidence eight steps

- Step one - Articulating the review question. This is important as it not only guides the researcher in conducting the review but also assists readers to discern whether or not they should read it. A good question should include the four elements of a population, an intervention, a comparison intervention and outcome measures.³⁰ The mnemonic (PICO) is commonly used for quantitative reviews and can also be used for qualitative reviews to assist in stipulating the inclusion criteria. Because qualitative systematic reviews do not measure outcomes, the qualitative systematic review will be reported according to the meta-synthesis of individual's experiences.³⁰
- Step two - Developing the research protocol. The development of a rigorous proposal is a vital process as it aims to ensure credibility with its research question, stated research methods and stated questions.²⁷ It is a requirement of the JBI systematic review process that all systematic reviews have an *a priori* published protocol.³¹
- Step three – Undertaking a comprehensive search strategy to identify all research studies relevant to the review. The standard JBI systematic review search strategy is a three-phase process. It begins with the identification of initial key words, followed by a preliminary search and the analysis of the text words contained in the title and abstract, and of the index terms used to describe the relevant articles found. In step two a second search using all identified keywords and index terms are undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles are searched for additional studies.²⁵
- Step four - Establishing a process for critically appraising the quality of each study. The JBI QARI checklist has been devised to appraise qualitative studies. This checklist is a standardized tool that is used independently by both the primary

reviewer and the secondary reviewer to critically appraise the full text of studies that meet the protocol inclusion criteria in relation to the review question and study methods. The purpose of critical appraisal is twofold as it will exclude studies that are of low quality, and it will also identify strengths and limitations of included studies.³²

- Step five - Extracting the data using the standardized JBI data extraction tool. Components of the data extraction include; information regarding the methodology used, the method, the phenomenon of interest, the setting, geographical location, culture, participants, and method of data analysis and the authors' conclusions. Specific findings are also extracted with a level of credibility allocated to each finding consistent with the congruency between the finding and the supporting data from the primary study.²⁵ A grade (unequivocal, credible, or unsupported) is allocated depending on the level of credibility. Unequivocal is allocated when the evidence supporting the finding is beyond reasonable doubt and not open to challenge. Credible is allocated when the evidence is plausible and logically inferred from the data, but may be open to challenge. Unsupported is when findings are not supported by the data.²⁵ The tool also allows for reviewers to note their comments.
- Step six – Synthesizing data. Qualitative research findings are pooled using the JBI QARI method, which involves the aggregation or synthesis of findings to generate a set of statements that represent that aggregation.²⁵ Based on similarity of meaning the findings are collated to form user-defined categories and 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.²⁵ In effect meta-synthesis is a process of combining the findings of individual qualitative studies to create summary statements that authentically describe meaning of the themes. It is an interpretive process but requires transparency of process.²⁸
- Step seven - Interpreting the findings and developing recommendations based on the identified evidence. The JBI and collaborating entities currently assign a Grade of Recommendation to all recommendations made in its Systematic Reviews with a grade A for a strong level of evidence or a grade B for a weak level of evidence, which alerts the reader to its clinical significance.³³ It is also important in the final presentation that implications for practice are discussed, as well as implications

for further research The JBI and collaborating entities currently assign a Grade of Recommendation to all recommendations made in its Systematic Reviews with a grade A for a strong level of evidence or a grade B for a weak level of evidence, which alerts the reader to its clinical significance.³⁴ It is also important in the final presentation that implications for practice are discussed, as well as implications for further research and limitations and conclusions.

- Step eight – Reporting. It is a requirement that authors begin a systematic review with a ‘plain language’ summary. The Preferred Method of Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) has become the international standard.³³ The PRISMA statement must include a flow diagram with the unique number of records identified by the searches, the number of records excluded, the number of records retrieved in full text, the number of studies excluded after assessment of full text and the number of studies that meet the eligibility criteria for review and the number of studies contributing to the main outcome. The description of studies may include details of included studies, assessment of methodological quality, characteristics of the participants and phenomenon/phenomena studied.²⁵

The JBI approach uses a software program called JBI SUMARI (System for the Unified Management, Assessment and Review of Information). Two components of this software were used within this dissertation JBI CREMS (Comprehensive Review Management System) and JBI QARI (Qualitative Assessment and Review Instrument). JBI CREMS software guides the researcher with the initial protocol, study selection and descriptive data extraction. The JBI QARI is designed to manage, appraise, extract and synthesize qualitative data. It employs a standardized tool to review qualitative studies and synthesize the findings of qualitative studies. Whilst the Critical Appraisal Skills Program (CASP) is the most frequently used tool to appraise qualitative papers it has been noted by some that it does not score well in evaluating the intrinsic methodology quality of an original study when compared with the other instruments such as the JBI critical appraisal instrument.³⁵ The JBI is recognized as one of the leading international organizations providing method guidance and tools for systematic review of qualitative evidence.³⁵

1.4 Definitions

- Within this dissertation the term carer refers to an individual who provides personal care, support and assistance to an older person who is in need of support and does not receive payment for this care, with the exception of government benefits.⁸
- The term “care-receiver” in this dissertation refers to the person receiving care.
- An “older person” in this dissertation refers to an individual who is 65 years or over, or a person under 65 years of age with an age related condition, which necessitates the need to be admitted into a residential aged care facility (RACF).
- An “age related condition” may be an early onset of dementia or a physical disability. It is acknowledged internationally that indigenous persons may have age related conditions.
- The term “ACAT” refers to the Australian aged care assessment team, the government authorised staff who assess frail and aged people for eligibility for admission to a government subsidized RACF. Other countries do not use this term, the term “authorised person” is often used to assess people requiring aged care services.
- The term “RACF” refers to a residential aged care facility which provides nursing and personal care to aged people and or people with age related illnesses who require care that cannot be provided in their home. The RACF can be either funded wholly or partly by government, or be privately run facilities for-profit or not for-profit.

1.5 Systematic review objective

The question addressed in the review was what is the experience of carers when the person they have been providing care for is admitted into a RACF, with the expectation that this will be permanent?

The primary objective of the review reported on in this dissertation was to enhance understanding about the experiences of carers of older people when the person they have been providing care for is admitted permanently into a RACF. A secondary objective was to provide evidence that could be used to enhance the care of carers of aged people, by improving the practices of hospital staff and aged care workers in RACFs within Australia.

1.6 Structure of the dissertation

This dissertation is organized into four chapters. In addition to this background chapter the second chapter outlines the systematic review inclusion criteria, search strategy, assessment of methodological quality, and data extraction and synthesis processes. The third chapter describes the results and the findings of the systematic review. The final chapter summarizes the main findings of the review and reflects on their significance, highlights knowledge gaps, draws out the inferences of the review for research and practice, and flags the limitations of the review.

Chapter 2 – Systematic review method

This chapter outlines the methods used in the systematic review reported in this thesis. It firstly describes the inclusion criteria covering types of studies, participants, the phenomenon of interest, and context. This is followed by description of the search strategy, method used to assess methodological quality of included studies, data extraction and data synthesis methods.

2.1. Inclusion Criteria

2.1.1. Types of studies

This systematic review considered for inclusion all qualitative studies published in English that examined the phenomenon of interest including but not limited to research designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

2.1.2. Types of participants

The systematic review considered studies for inclusion whose carer participants were providing unpaid support, care and assistance to an older person prior to the care-receiver's admission to a RACF permanently. Carers of all ages were included irrespective of the time in the caring role, whether they resided together or not, or the length of time living together.

Carers were considered regardless of their relationship, age, sex, ethnic origin and socioeconomic status. This was because a secondary objective of the review was to make recommendations for best practice strategy that support carers of older persons who have admitted someone they have been caring for into a RACF permanently. This required comprehensive coverage of all groups of carers and if findings of studies permitted, any differences in experiences and the need for support across sub groups, for example by relationship, age, ethnic origin/language, sex and socio-economic status.

2.1.3. Phenomenon of Interest

The phenomenon of interest in the systematic review was the experiences of the carer

of an older person and/or person with an age-related condition requiring to be admitted into a RACF permanently. Carers' experiences were reflections on the pre-move, at decision-making time, during and post-move when the person they have been caring for at home is admitted into a RACF permanently.

2.1.4. Context

The review considered studies conducted in developed countries examining experiences of carers of any ethnicity and culture. While there is no one set definition of a developed country, countries with a 'very high human development index' were included in this review.³⁶ Studies with participants from developing countries were excluded, as the aim was to use the review findings to draw inferences for best practice support of carers in developed countries such as Australia and other international countries with similar years of life expectancy for their residents and industrialization progress.

All RACFs were included in this review including government subsidized RACFs and non-government funded RACFs and some with full government funding such as in Sweden. There was an expectation that the older person or person with an age-related illness required a level of personal care, nursing assistance and support with their activities of daily living and would receive such care in the RACF when it could no longer be provided in their home environment.

2.2. Search strategy

A comprehensive search strategy was used to find both published and unpublished studies written in English, as no translation services were available. A three-step search strategy was utilized. In step one a limited search of MEDLINE, CINAHL, JBI Library and Google Scholar was undertaken and the text words contained in the title and abstract, and the index terms used to describe the article were examined to identify relevant search terms. In step two a second search using all identified keywords and index terms were undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. No date restriction was applied in the search, as there was value in understanding carers' experiences over time.

The databases searched for studies published in the commercial (black) literature were: PubMed/MEDLINE, CINAHL, PsychINFO, Scopus and Embase, reaching saturation with no additional studies identified from Embase.

The search for unpublished (grey) Literature reporting qualitative studies included:

Mednar, ProQuest Dissertations and Thesis, Google Scholar.

Initial keywords used were carers of elderly, separation, experiences, residential aged care facility, qualitative.

Appendix I provides the search strategies used for the various databases.

2.3. Assessment of methodological quality

Qualitative papers selected for retrieval were assessed by two reviewers who worked independently for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from JBI QARI (Appendix II). Disagreements that arose between the reviewers were resolved through discussion and then with a third reviewer.

The reviewers discussed each item of the appraisal instrument prior to the secondary reviewer commencing their appraisal. Following the appraisal of the selected studies, the reviewers met and clarified their interpretation of the appraisal tool and discussed discrepancies in scoring. This included clarifying standards for inclusion or exclusion for the review. The methodological standard set for inclusion was that items 3,4,5,8 and 10 had to be met. The list of criteria can be seen in JBI QARI Appendix II. This meant that the studies had to show congruity between the research methodology and the methods used to collect data, the research methodology and the representation and analysis of data, and the research methodology and interpretation of the results; and to ensure participants voices were adequately represented and that the conclusion drawn in the research report flowed from the analysis or interpretation of the data,

2.4. Data extraction and synthesis method

Data were extracted from papers included in the review using the standardized data extraction tool from JBI QARI (Appendix III). The data extracted included specific details about the phenomenon of interest, populations and study methods and outcomes of significance to the review question and specific objectives. The descriptive data of interest

that were extracted included:

- Study type;
- Country and setting where the study was conducted (geographical and cultural);
- Participants (number, baseline demographics, age group, ethnicity);
- Phenomena of interest;
- Author's conclusions

These data are presented as characteristics of included studies in Table 2.

Qualitative study findings were extracted as themes identified by the authors of each study. The presentation of the themes varied, sometimes appearing as headings and sub headings in the text in the paper. These findings were extracted with one or more illustrations from the text to support the finding.

All findings were assigned one of three levels of credibility according to the following criteria:

- Unequivocal (U) - Assigned if the findings were related to the evidence beyond reasonable doubt, including findings that were matter of fact, directly reported/observed and not open to challenge. These findings were supported by illustrations in the form of direct quotes from participants, where the quote from the participant clearly supported the finding extracted.
- Credible (C) - Assigned to those findings that were, albeit interpretations, plausible in the light of the data in the study and/or the theoretical framework. They could be logically inferred from the data. These findings were supported by a direct quote from a participant.
- Unsupported (Un) - Assigned in cases where the study author's finding was not congruent with or supported by identifiable data. These findings were presented without any supportive data or text.

Unequivocal and credible findings were included in the meta-synthesis; findings that were deemed to be Unsupported were not considered for inclusion in the final synthesis.

Qualitative research findings from the included studies were pooled using the meta-aggregation approach advocated by JBI and the JBI QARI software tool for synthesizing qualitative research findings. This involved the aggregation or synthesis of findings to

generate a set of statements that represent that aggregation. Findings were grouped into categories that were created on the basis of similarity of meaning; categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that could be used as a basis for drawing evidence-based practice recommendations.

The data synthesis method of meta-aggregation used in this review is underpinned by the philosophical understanding of pragmatism, in particular Dewey's perception that pragmatism and the role of inquiry is concerned with transforming and evaluating features of situations.²⁸ This philosophical understanding aligns with using the meta-aggregative approach to synthesize qualitative findings as developed by JBI in that it aims to help understand and support what takes place in human practice, drawing on the pragmatist perspective to have a useful role in evidence-based practices in healthcare.³⁷

According to Finfgeld, meta-synthesis is a term referring to 'the synthesis of findings across multiple qualitative research reports to create a new interpretation'.²⁴ The use of meta-aggregation as the approach used in this systematic review of studies has its benefit in that it is a structured process which takes an inclusive approach to searching and selecting studies and is based on the development of a rigorous proposal or protocol. There is also an emphasis on the methodological quality of the studies that are included in the final synthesis. The meta-aggregation approach aggregates findings of included studies of high quality into categories and those categories are then synthesized, thus forming synthesized statements which represent 'lines of action'.³⁷ Whilst other methodological approaches such as a meta-ethnographic approach can be utilized in understanding a phenomenon of interest and its seven phases can be aligned to the systematic review process, there is no requirement to do so.³⁷

The meta-aggregation process undertaken within this dissertation involved a rigorous examination and interpretation of findings of a number of qualitative research studies. Synthesized findings were created with a transparent and auditable approach, and these were used to develop recommendations for research and practice.

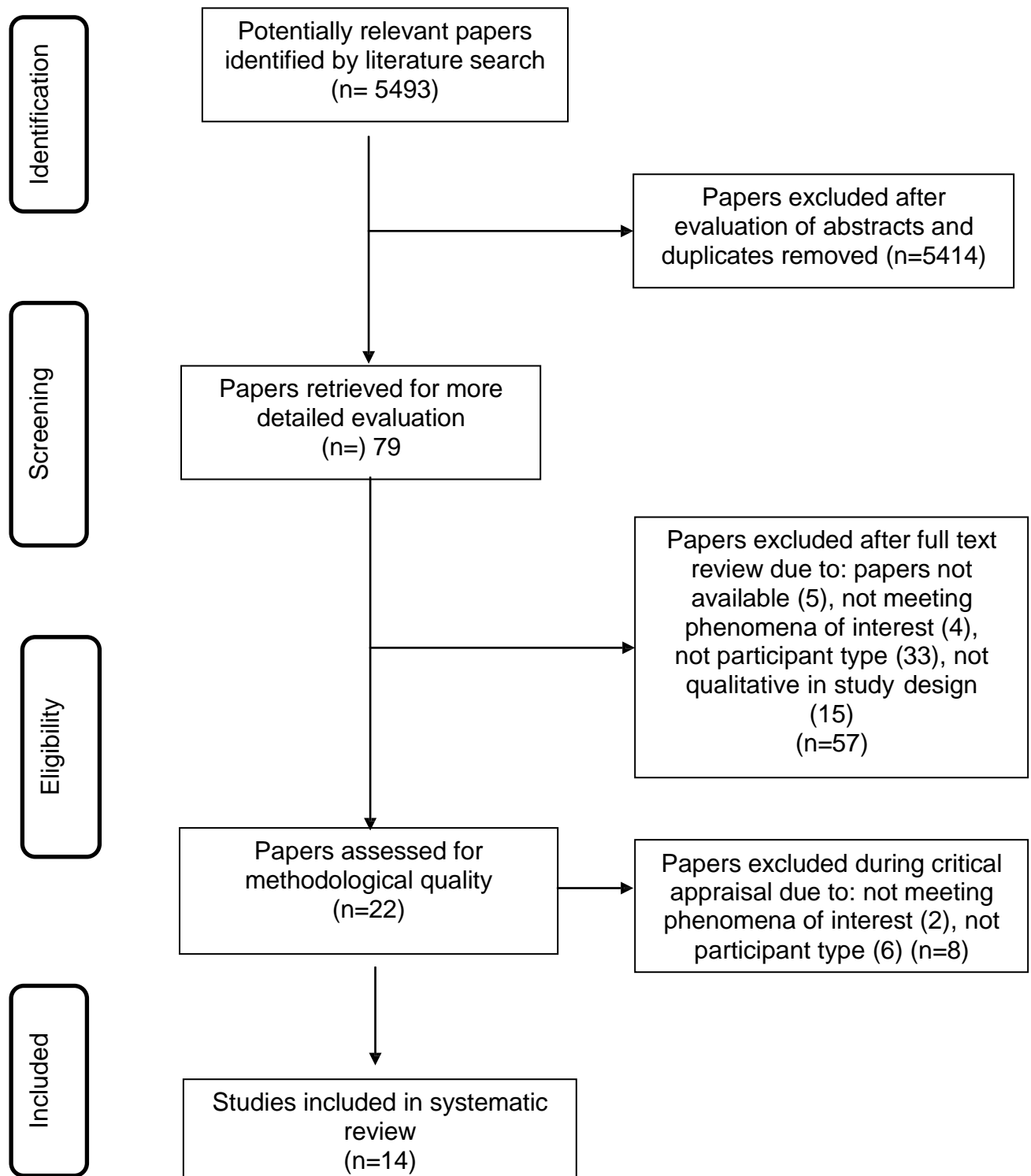
Chapter 3 – Results

This chapter is comprised of two sections. Section 3.1 describes the search results and study selection process, the methodological quality of included studies and their key characteristics. Section 3.2 presents the results from the analysis and synthesis of findings from the included studies on how carers experience admitting the person they have been caring for into a RACF permanently.

3.1. Description of studies

3.1.1. Search and study selection

Overall, 5,493 papers were identified by the search strategy across eight selected electronic databases of published and unpublished literature. After removing duplicates, 5,414 were examined against the inclusion criteria by reading the titles and abstracts. A total of 79 papers were retrieved for full-text examination. Fifty-seven papers were excluded after review of the full paper, including the five papers that could not be retrieved. No additional studies were identified from the reference lists of these papers. Twenty-two of the studies pulled for full text examination met the criteria for critical appraisal. During examination of these 22 full-text papers, an additional eight papers were excluded at this stage as they did not meet the inclusion criteria for type of participant and/or the phenomenon of interest. i.e they should have been excluded prior to appraisal, These exclusions resulted in 14 studies being critically appraised and included in the review. The results of the search strategy and study selection process are illustrated in Figure 2. Appendix IV lists the studies excluded at full text examination with the reasons for exclusion.



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Figure 2: Flow diagram detailing search results, retrieval and selection of studies

3.1.2. Methodological quality

The critical appraisal process comprised analysing each individual paper and allocating a score out of 10 according to 10 criteria on the JBI critical appraisal tool. The reviewers discussed each item of the appraisal instrument prior to the secondary reviewer commencing their appraisal. Following the appraisal of the selected studies, the reviewers met and clarified their interpretation of the appraisal tool and discussed discrepancies in scoring. This included clarifying standards for inclusion or exclusion for the review.

As indicated by Table 1, which reports the results of the methodological quality assessment, all 14 of the included studies included and critically appraised were found to be of a high or very high standard when assessed by the JBI tool. Two studies^{38,39} scored 10/10, three studies^{40,41,42} scored 9/10 (a score of 9 or more was classified as very high standard), five studies^{10,43,44,45,46} scored 8/10 and four studies^{47,48,49,50} scored 7/10 (scores of 7 and 8 were classified as high standard).

As explained above, to be included studies had to meet the quality criteria. In addition five questions in the JBI quality appraisal tool were identified as essential. Those questions were items 3, 4, 5, 8 and 10 in the JBI QARI (Appendix II) The following summarizes the studies' reported compliance to the remaining five criteria in the JBI quality appraisal tool:

- All except one study achieved compliance for criterion 1, which assesses whether the philosophical perspective of the study is clear.⁴⁷
- All 14 studies were compliant with criterion 2, which assesses congruence between the research methodology and the research objectives.
10,38,39,40,41,42,43,44,45,46,47,48,49,50
- Half of the studies were compliant with criterion 6, which requires that author(s) provide a statement locating researchers culturally or theoretically in relation to the study.10,38,39,40,41,42,47
- Only three of the 14 studies were compliant with criterion 7, which assesses whether the researcher(s) reported how their perspective(s) may have influenced the research/findings.^{38,39,41}
- A total of eight of the 14 studies were compliant with criterion 9, assessing whether ethical approval for the study had been sought.38,39,40,42,43,44,45,46

To conclude the description of methodological quality, the evidence base used in this

review is of a high standard. The main source of potential bias/concern about validity of primary qualitative studies on which the synthesized findings reported below are based - which are limited – relate to the potential influence of researchers on interpretation of study findings.

Table 1: Assessment of included study quality

Citation	Q 1 Congruity between philosophical perspective and research methodology	Q 2 Congruity between research methodology and research objective	Q 3 Congruity between research methodology and data collection methods	Q 4 Congruity between research methodology and analysis of data represented	Q 5 Congruity between research methodology and interpretation of results	Q 6 Statement locating the researcher culturally or theoretically	Q 7 Influence of the researcher on the research addressed	Q 8 Participants and their voices adequately represented	Q 9 Evidence of ethical approval	Q 10 Conclusion drawn flow from the analysis	Rating
Ryan A, Scullion H. 2000 ¹⁰	Y	Y	Y	Y	Y	Y	U	Y	U	Y	High
Ryan A, McKenna H. 2013 ³⁸	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Very High
Ryan A, McKenna H, et al. 2012 ³⁹	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Very High
Kellett U. 1999 ⁴⁰	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Very High
Kwon S, Tae Y. 2012 ⁴¹	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Very High
Strang V, Koop P, et al. 2006 ⁴²	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Very High

Eriksson H, Sandberg J. 2008 ⁴³	Y	Y	Y	Y	Y	U	N	Y	Y	Y	High
Lundh U, Sandberg J, et al. 2000 ⁴⁴	Y	Y	Y	Y	Y	U	U	Y	Y	Y	High
Penrod J, Dellasega C. 1998 ⁴⁵	Y	Y	Y	Y	Y	U	N	Y	Y	Y	High
Sussman T, Dupuis S. 2012 ⁴⁶	Y	Y	Y	Y	Y	U	N	Y	Y	Y	High
Park M, Butcher H, et al. 2004 ⁴⁷	U	Y	Y	Y	Y	Y	U	Y	N	Y	High
Reuss G, Dupuis S, et al. 2005 ⁴⁸	Y	Y	Y	Y	Y	U	U	Y	U	Y	High
Tilse, C. 1998 ⁴⁹	Y	Y	Y	Y	Y	U	U	Y	N	Y	High
Tilse, C. 1994 ⁵⁰	Y	Y	Y	Y	Y	N	N	Y	N	Y	High
%	92.86	100.0	100.0	100.0	100.0	50.00	21.43	100.0	57.14	100.00	

3.1.3. Characteristics of included studies

The key characteristics of each included study are presented in Table 2. This section describes the characteristics of the studies overall.

The included studies were published over a 19 year period (1994 – 2013) with six studies^{10,31,35,36,40,41} published over a decade ago and eight ^{29,30,32,33,34,37,38,39} published from 2004 onwards. Studies conclusions a decade ago are similar to recent studies indicating that support was required during the critical transition stage to a RACF.

Types of studies

All 14 studies were exploratory, describing their methodological approach as qualitative. The author of one study stated specifically that hermeneutic approach had been used.⁴⁰ Six authors specifically stated a grounded theory approach was used.^{10,38,41,44,45,46} One author specified a constructivist approach was used.⁴³ Another author specified symbolic interactionism was used.⁴⁸

Of the remaining five studies which did not describe their approach beyond the statement that it was qualitative.^{39,42,47,49,50} One author conducted a content analysis from the in-depth interviews.⁴⁹ Another author conducted direct observations and in-depth interviews.⁵⁰ Two other authors^{39,47} specified that semi-structured interviews were undertaken and the remaining author⁴² specified that explorative descriptive analysis from the open-ended questions was conducted. Eight of the studies^{10,38,40,41,42,43,47,48} provided examples of their open-ended questions and for the six studies that did not provide their specific questions it was able to be inferred that an exploratory approach was pursued.^{39,44,45,46,49,50}

The six studies that used grounded theory to explore individuals' meanings of the experience of admitting the person they had been caring for into a RACF provided rich specific data from individual carers, which was checked for accuracy of interpretation during the interview or at a second follow-up interview with the carer.^{10,38,41,44,45,46} Another author used the Luborsky method for thematic analysis which identified

frequently used phrases or words after having interviewed until saturation had been achieved.⁴⁷ One other study guided by symbolic interactionism also used semi-structured interviews to gather experiences until no other new experiences emerged.⁴⁸

The synthesis of the qualitative evidence presented below of how carers experience the process of someone they have been caring for being admitted permanently into RACF is therefore based on studies that used a variety of qualitative methodologies and methods.

Participants

Care-giver characteristics

Of the 14 studies, four included spousal carer participants.^{43,44,49,50} Of these, one included only male spousal carers.⁴³ One study included solely adult children.⁴¹ The carer research participants in the remaining nine studies were mixed including spouses (male and females), adult children (sons and daughters) siblings, daughters-in-law, nieces, nephews, grand-daughters, grand-daughter-in-law, friends and a guardian.
10,38,39,40,42,45,46,47,48

Across the 14 studies, the total carer participant number was 247 of which 163 were females, 66 males and 18 individuals neither identified as male or female. Only one study did not identify the gender of carers.⁵⁰ A total of 13 studies included at least one spouse in the carer participants.^{10,38,39,40,42,43,44,45,46,47,48,49,50} From the total 247 carers 85 were spousal carers, with 33 identified as female and 21 male. Three of the studies did not report on the gender of the remaining 31 spouses.^{42,48,50}

The number of adult child carers in the participant sample of the included studies is large. There were 75 daughters, 32 sons, 16 daughters-in law, three sisters, two brothers, five nieces, four nephews, two grand-daughters and one grand-daughter-in-law, as well as 18 adult-children (not identified as male or female) one sibling (not identified as male or female) two friends/guardian (not identified as male or female) and one of unknown relationship. From the 14 studies, four did not reveal the age of carers.^{38,39,40,46} Within the other 10 studies ages ranged from 26 to 93 years.^{10,41,42,43,44,45,47,48,49,50} One of the studies calculated the mean age of the spousal carer as 75.7years for females and 78.6 years for males.⁴⁹ Another study reported the mean age of family carers as 60.4 years.⁴²

The length of time that the carer was in the caring role prior to the older person being admitted into a RACF was revealed in only four of the 14 included studies.^{41,42,43,47} Within these studies the length of time caring was reported as ranging from one to 17 years.^{41,42,43,47} Seven of the 14 studies reported the time frame that the person had been in the RACF at the time the carers participated in the study.^{10,42,43,44,46,48,50} Interviews were held from within a month of the person being admitted to a RACF and up to three and a half years afterwards.

To summarize the main characteristics of the care-giver participants in the 14 studies: The participants (247) included not only spouses but also daughters and sons, as well as other relatives. There were more than double the number of daughters compared to sons, and female carers exceeded the number of male carers in the spouse participants. The predominance of female carers is well documented in the literature and hence this characteristic of the participants is not surprising.³ The age of the carers varied, and included other than elderly individuals.

Characteristics of the care-receiver

All 14 included studies involved the caring of a person with dementia and/or high care needs due to physical disability. Only three studies identified ages of the care-receiver, all who were 65 years and older and up to 100 years.^{45,47,48} There were only three studies in which all the care-receiver participants were identified as persons living with dementia.^{41,42,47} The other 11 studies included people being cared for who had dementia and/or a physical need for assistance.^{10,38,39,40,43,44,45,46,48,49,50} In the four studies where spouses cared for their partners, RACF placement was often triggered when the carers' health declined, or the care-receivers' physical needs could no longer be managed in the home by the carer.^{43,44,49,50}

From the 14 studies, seven reported residing together, prior to the permanent move to a RACF.^{41,43,44,46,47,49,50} Four studies specified that the care-receiver resided with their spousal carer.^{43,44,49,50} The other three studies reported that the care-receiver resided with a carer other than their spouse.^{41,46,47} The remaining seven studies did not specify where the care-receiver resided prior to being admitted into a RACF.^{10,38,39,40,42,45,48} At times the person was moved direct from hospital to a RACF.^{10,39,44,45,46,48,49,50}

Study settings

The studies were conducted in six different developed countries. Three were conducted in Australia^{39,49,50} three in Canada^{42,46,48} three in the United Kingdom^{10,38,39} two in Sweden^{43,44} two in South Korea^{41,47} and one in the United States of America.⁴⁵ All are developed countries with similar life expectancy and rank ‘ very high ‘ on the Human Development Index compared to other countries.³⁶

A majority (11 out of 14) of the studies explored the experiences of participants living in metropolitan areas.^{10,40,41,42,44,45,46,47,48,49,50} Another study was in the central part of a country.³⁴ The settings included private, community-based, state and public government owned RACFs with some for-profit and not-for-profit. Only one of the studies was conducted in an acute care hospital where the care-receivers were in-patients at the time.⁴⁵ The remaining study which had two publications explored experiences of those living in rural or remote areas with a range of small/large, family/non-family owned homes.^{38,39}

Table 2: Key characteristics of included studies

Study	Phenomenon of Interest / Objective	Method	Participants (Carers) M = males F = females	Participants (Carees) M = males F = females	Setting
Ryan A, Scullian H. 2000 ¹⁰	To explore family carers' thoughts and feelings about placing their older relative in a nursing home.	Grounded theory using interview schedule	10 relatives 3 M, 7 F, 5 aged over 60 yrs, 5 aged 41 to 60 yrs. Time as carer not specified. (includes 1 wife)	Dementia more than physical disability, no gender or age provided, some in hospital pre move to RACF	Four nursing homes in Northern Ireland
Kellet U. 1999 ⁴⁰	To explore families' experience of nursing home placement.	Hermeneutic phenomenology	7 relatives 1 M, 6 F, no ages provided. Time as carer not specified. (includes 1 wife)	Dementia and physical disability, no gender or age provided, nor pre-move transfer details	Two private nursing homes in metropolitan area in Australia
Lundh U, Sandberg J, et al. 2000 ⁴⁴	To explore the experiences of spouses who have placed a partner in a care home for older people.	Grounded theory using interview schedule	14 spouses 3 M, 11 F, aged 68 to 90 yrs. Time as carer not specified	Dementia 3, physical disability 11, no gender or age provided, some in hospital pre move	Small town care-home in Sweden
Penrod J, Dellasega C. 1998 ⁴⁵	To explore the experiences of caregivers actively involved in the process of placing an older adult in a long term care facility upon discharge from hospital.	Grounded theory using interview schedule	10 relatives 2 M, 8 F, aged 35 to 80 yrs, 5 over 65, 5 under 65 yrs. Time as carer not specified. (includes 2 wives)	Musculoskeletal disability more than dementia, aged 65 to 100yrs 75% F. All 10 in hospital pre-move	Hospital pre-move to a long-term care facility in Pennsylvania US
Tilse C. 1998 ⁴⁹	To explore the meaning of placing a spouse in long term care and highlight the particular experiences of carers of spouses with dementia by contrasting their accounts of the experience with those of spouses who had placed a partner as a result of a physical disability.	Qualitative in depth interviews and content analysis	18 spouses 9 M, 9 F aged 62 to 89 yrs. Mean age for F 75.7 and M 78.6 yrs Time as carer not specified	Dementia 5 M, 5 F, physical disability, 1 M, 4 F and 3 M with dementia and physical disability. Some in hospital pre move	Six metropolitan RACFs community owned, private and government nursing homes in Australia

Tilse C. 1994 ⁵⁰	To explore how residential facilities treat family members who have placed a long term partner and to link an understanding of the experience.	Qualitative in depth interviews and direct observations	18 long term partners no gender provided aged over 60 yrs. Time as carers not specified	No disability type, gender or age provided, some where transferred from hospital	Six SE Qld RACFs community based hostel, private and state government nursing home in Australia
Eriksson H, Sandberg J. 2008 ⁴³	To describe from a gender identity perspective the experiences of older men involved in the process of caring for a partner at home and the placement into a nursing home.	Qualitative interviews – constructivist approach	7 M spouses aged 67 to 93 yrs. One to 14 yrs as carer	Dementia and physical disability, no age or gender provided, nor transfer details	Metropolitan nursing home in Sweden
Kwon S, Tae Y. 2012 ⁴¹	To explore and describe the process of nursing home placement decision-making and adaptation among adult children caregivers of demented parents in Korea.	Grounded theory using in depth unstructured interviews	16 adult children 5 M, 11 F, aged 37 to 70 yrs, 2 in 30s, 4 in 40s, 7 in 50s, 2 in 60s, 1 in 70s. Carer for 1.5 to 8 yrs	Dementia, no age or gender provided. Pre move resided with carer 8 others not specified	Three RACFs in a large metropolitan city in Korea
Park M, Butcher H, et al. 2004 ⁴⁷	To provide an in-depth description of Korean family caregivers experiences in making the decision to place a family member with dementia in a Korean long term care facility.	Qualitative - semi structured interviews	19 relatives 8 M, 11 F, aged 36 to 65 yrs. Average 3yrs as carer. (includes 1 wife)	Dementia 3 M, 16 F, aged 60 to 91 yrs. Pre move resided with spouse 5, adult child 9, alone 5	Ten RACFs including geriatric hospitals, dementia care, 6 for-profit, 2 not-for-profit and 2 public/ government in suburban area Korea
Reuss G, Dupuis S, et al. 2005 ⁴⁸	To develop an understanding of family member's experiences of moving a loved one to a long term care facility and to identify ways in which facilities might help ease this process.	Qualitative in depth semi-structured interviews - symbolic interactionism	21 relatives 2 M, 19 F, aged 30s to 70s, 4 in 30s, 4 in 40s, 6 in 50s, 2 in 60s, 5 in 70s. Time as carer not specified. (includes 5 spouses)	Dementia 13, physical disability 8, aged over 70 yrs with 12 over 80 yrs. Moved from hospital 5, from home or their carer's home 6, from other care facilities 10	Three RACFs, privately and publicly owned in metropolitan area Canada

Ryan A, McKenna H. 2013 ³⁸	To explore rural family carers' experience of the nursing home placement of an older relative.	Grounded theory using semi-structured interviews	29 relatives 8 M, 21 F, no ages provided. Time as carers not specified. (includes 3 wives)	Dementia and physical disability, no ages or gender provided nor transfer details	Small/large family/non family owned homes in rural isolated area in Northern Ireland
Ryan A, McKenna H, et al. 2012 ³⁹	To explore rural family carers' experiences of the nursing home placement of an older relative.	Qualitative semi-structured interviews	29 relatives 8 M, 21 F, no ages provided. Time as carers not specified. (includes 3 wives)	Dementia and physical disability, no ages or gender provided. Moved from hospital 18, from home 8, from other care facilities 3	Rural RACF in Northern Ireland
Strang V, Koop M, et al. 2006 ⁴²	To explore family caregiver's experiences while they waited placement of family members with dementia in long term care and how they coped during this period of waiting and transition.	Qualitative open ended interviews – explorative descriptive analysis	29 relatives including 2 friends 7 M, 22 F, aged 26 to 88 yrs with a mean of 60.4 yrs. Carer from 1 to 17 yrs. (includes 8 spouses)	Dementia 29, no ages or gender provided nor pre move transfer details	RACF in Edmonton a capital city in Canada
Sussman T, Dupuis S. 2012 ⁴⁶	To explore family members' experiences supporting a relative's move into a long-term care home.	Grounded theory semi-structured interviews	20 relatives 3 M, 17 F, no ages provided. Time as carers not specified. (includes 3 wives)	Dementia 13, physical disability 7. Moved from hospital 8, from home 6, from retirement home 6	Three privately owned RACFs in a large city Ontario Canada

3.2. Synthesized findings

A total of 71 relevant findings addressing the question of interest were extracted from the included studies. From the 71 relevant findings, 32 were deemed to have an unequivocal level of credibility and 39 were deemed to have a credible level of credibility. There were no unsupported findings included in this review. All the unequivocal and credible findings were supported by the data presented in the studies, and were pooled to generate synthesized findings (see Table 3). The following table provides an overview of the levels of credibility in each synthesized finding. The meta-synthesis represents a selection of carers' experiences from Australia, Canada, Sweden, South Korea, the United Kingdom (Northern Ireland) and United States of America.

Table 3: Summary of evidence credibility for all synthesized findings

Synthesized Finding (SF)	Unequivocal (U)	Credible (C)	Unsupported	Total
SF 1	14	18	0	32
SF 2	10	11	0	21
SF 3	8	10	0	18
Overall Total	32	39	0	71

Meta-synthesis of the findings from the 14 studies generated three synthesized findings, after the findings were grouped into user-defined categories created on the basis of similarity in description of carers' experiences of admitting the person they have been caring for into a RACF permanently. The three synthesized findings were derived from seven categories developed by considering similarity of meaning across the 71 study findings. All the study findings with a supporting illustration are listed in Appendix V.

The synthesis results are presented below. The presentation is organized by synthesized findings. For each synthesized finding a description of the categories derived from the findings is provided. Some illustrative participant voices that informed the primary study findings are also offered to enhance understanding the dimensions of the experience captured by each synthesized finding.

3.2.1. Synthesized finding 1 (Figure 3)

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.

The first synthesized finding was derived from three categories underpinned by a total of 32 findings. A summary of each of the three categories is provided below, together with a few key illustrations that support them. Full details of findings and illustrations are presented in Appendix V.

Category 1.1: Carers often experience mixed feelings of guilt, loss of control, sadness and relief simultaneously and possess a sense of failure when the decision to place is made.

This category was developed from 14 findings with similar meaning. These findings indicated that often carers experienced mixed feelings, including relief from the burden of physical care, sadness at the loss of their partner/companion and feelings of ambivalence, inadequacy and a sense of failure at not being able to continue to provide the care needed. Carers felt guilty putting the person out of their home; some felt like parents abandoning their baby when admitting the person in a RACF. Most carers experienced feelings of apprehension, in particular when they were from cultures where there was an expectation that children would look after their parents. The eastern tradition of filial piety impacted on some family carers as they struggled with the stigma of what other people would say about them, but felt that they had no other choice but to pay for the older person to go into a RACF. These findings show that the feelings of uncertainty, a sense of failure and sorrow were reinforced after admission to RACF, further impacting on carer's feelings of guilt.

The findings indicated that carers had feelings of powerlessness, felt unable to control the situation and experienced high levels of distress when the decision was made to admit the older person into a RACF especially directly from hospital. Carers often experienced conflicted and ambivalent feelings of relief and feeling pressured, as, once the decision was made in the hospital, carers felt they could not change their mind and the focus was on prompt discharge and taking the first available RACF bed.

Illustrations of the experience described by the findings in this category:

"You feel so guilty that you were so inadequate as a daughter or as a child of a parent that has to be put into a residential care. The guilt is so terrible, and it doesn't get any easier,

as time goes on you still feel guilty, but you try your best to make things as tolerable as possible".^{10(p1192)}

"Really, the hospital says, "We'll tell you what, you have to make an application, but you sign it and we pretend that that's your choice. "I would have been happier if the hospital just said, "Because we can't keep you in an acute care bed we're gonna transfer you here," then [there would be none of this sort of pretence that this "let's pretend that the family has a choice, let's pretend that the patient has a choice" – there really is no choice..^{37(p402)}

Category 1.2: Carers often experience a crisis as a pre-cursor to nursing home placement and find they are unable to cope and care for their relative.

The findings that informed this category (of which there were seven) revealed that feelings of exhaustion, and not being able to cope and continue in the care giving role often precipitated admission. No options or choices, other than RACF admission were highlighted by carers in most studies.

Another similar theme in these findings was that adult children as carers experienced crisis calls from the parents' place of residence, and at times from retirement village management, regarding their parents' behaviour. At times the calls related to the older person not eating properly, not attending the common area on time for meals, not taking their medications and having an increase in falls. These are often indications that the person's care needs have increased beyond the point of where they can live alone in a retirement village. Exasperation about the repetitive and unacceptable behaviours of the person with dementia often culminated in reaching a crisis point. Adult children in particular felt unable to cope with the continuing demand to care for the person in their home. Often the declining health of the older person and/or carer necessitated hospitalization. Whilst there had been crises, some carers had not realized the extent of the cognitive decline and deterioration in those with dementia.

The findings indicated that crises often precipitated unplanned admission to a RACF. Carers often experienced feelings of shock when the older person was transferred direct to a RACF after an admission to hospital. Handing over care to the RACF was very difficult for carers as they knew what the person's needs were, even though they could not cope any longer. For some even after a period of respite the carer could not

take the person back home, due to their exhaustion and inability to provide the ongoing care. Carers were prepared to take on the additional financial burden when admitting their relative in a RACF to assist with their coping. Only after admission to a RACF did some carers consider there may have been other options that had not been explored.

Illustrations of the data supporting the findings in this category:

“Just basically – with her falls, not eating properly (she was diabetic so she wasn’t taking her insulin and she was legally blind so we weren’t even sure if she was reading the numbers right when she was testing her sugar) – and we finally said look, we can’t do this any more, running over there all the time. I think it’s (time) we have a look at other alternatives”.^{37(p40)}

“He used to leave the faucet running all night and peep into other’s rooms at night. Kids hated it ... and he used to curse at them so often. And one day, we found him washing his face with the water in the toilet. We were so shocked to see that”.^{32(p147)}

Category 1.3: Carers often felt forced to make the difficult decision to admit the person in a RACF and sought support and validation from others.

This category was developed from 11 findings. They revealed that carers often felt that they had been forced to make negative choices, which at times were at odds with their embedded cultural values about how to care for family. The findings reveal that families often felt the need to justify their decision by emphasizing that others also agreed that it was not in the interests of either their own health or the older person’s health. Carers often felt they had minimal control of the decision-making and the process of admission to the RACF, and sought validation from health care professionals, other family, and friends. Some family members not in the caring role blamed the carer after the older person had been admitted into a RACF.

The findings indicate that carers sought support pre-move to RACF but often did not receive adequate support from family and care providers to keep caring for the person at

home. Not knowing who to talk to regarding their situation was another concern for carers. Some families reported the pre-move experience from hospital as horrendous, having to make life-changing decisions with little information and no other options provided. The findings illustrate the need for support and information pre-move to RACF, during the decision-making time, during the transition to RACF and following the move.

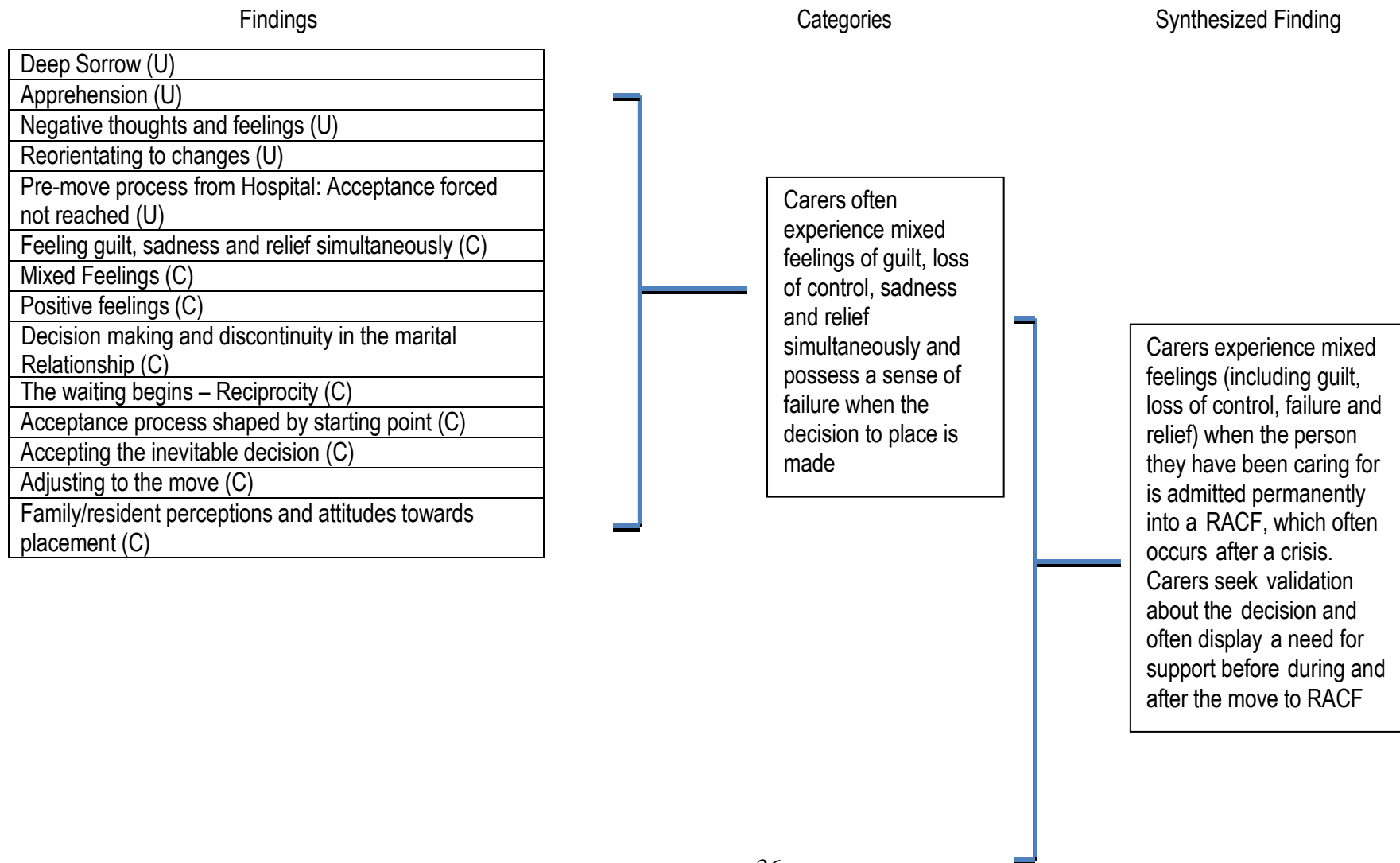
Illustrations of the data supporting the findings in this category:

“And she [social worker] said, it's a big job. And again, she seemed from her body language, to be agreeing with like, oh, okay, I think - and you look for that sort of validation. You look for that, like have I made the right decision”.^{36(p715)}

“it was the health workers and the doctor, they said she would have to go into a home”.^{10(p1191)}

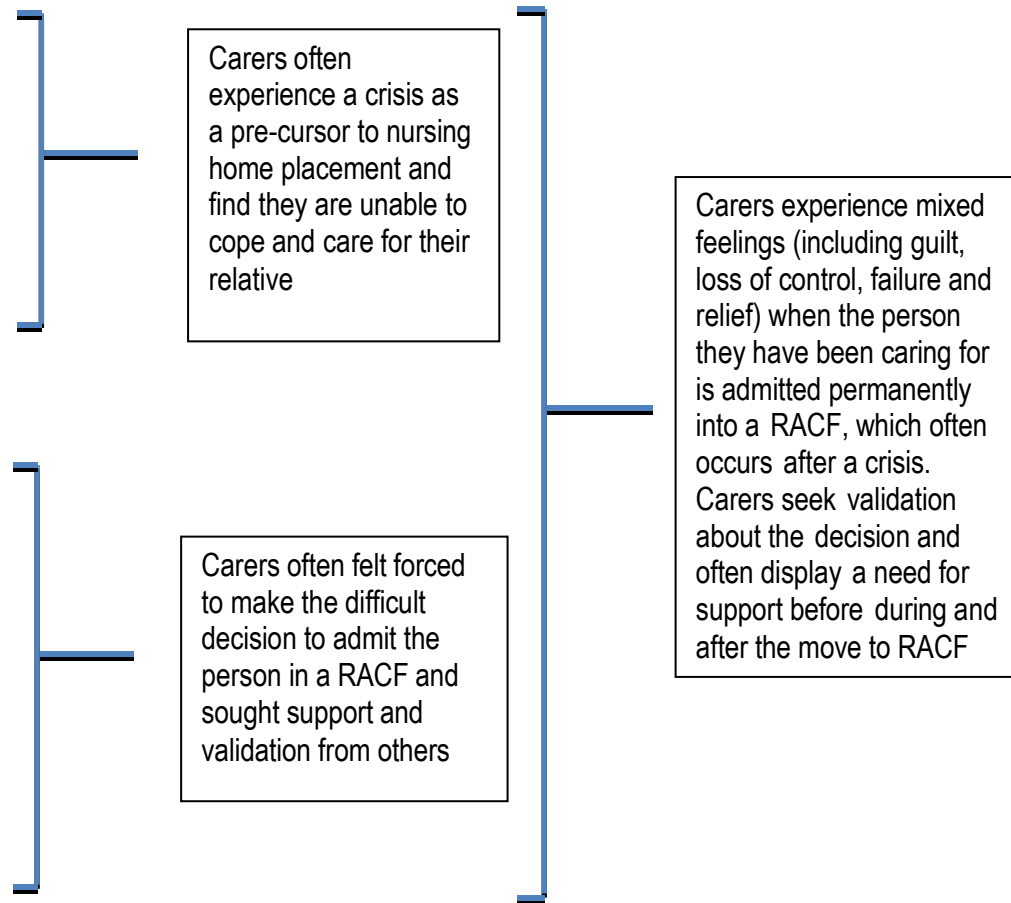
“If I didn't have two sisters, I don't know how we could do it. (One sister) basically looked after mom that moving day and (my other sister) and I and our husbands helped with the move and got a moving company...(that) was the only thing that helped that day, because it was such a stressful day”.^{39(p32-33)}

Figure 3. Meta-aggregative synthesis summary for synthesized finding 1: Carers' mixed feelings, crisis and need for support



The waiting begins – crisis as initiator (U)
Pre-move process from home: Acceptance through reflection and escalating needs (U)
Pre-move process from retirement residence: Mounting complaints with little time for reflection thwarts acceptance (U)
The precursors of the placement (C)
Realizing a dead end (C)
Seeking a way out (C)
Uncertainty (C)

Support from others (U)
Fractured Relationships (U)
Family and health care professional's influence in the decision making process (U)
No place like home (U)
Inability to cope (U)
Feeling exhausted (U)
Health status (C)
Carer Advocate (C)
Validation of the experience (C)
The waiting begins - control (C)
Making the decision (C)



3.2.2. Synthesized finding 2 (Figure 4)

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.

The second synthesized finding was derived from two categories underpinned by a total of 21 findings. Below, a summary of each of the categories is provided together with a few key illustrations that support them.

Category 2.1: Carers often experience difficulty in continuing a relationship with their spouses and visited frequently to alleviate their feelings of sadness, loneliness and to maintain a sense of continuity.

A total of seven findings described this aspect of the carers' experience. These suggest that maintaining continuity after admission of the person to a RACF was difficult for many but that commonly carers want to continue the relationship. The findings show that many spouses, both male and female, struggled with their feelings of obligation to care for each other. Spousal carers had feelings of attachment and remained loyal to their partners no matter how bad things became. Visiting helped some spouses to avoid the loneliness of living alone and enabled an opportunity for them to express their connection with their spouse. The findings facilitate understanding that carers often visited after admission to the RACF to make sure their spouse was looked after.

The findings in this category showed that carers also felt things were taken out of their control, and wanted to continue to have a level of involvement. In most cases the decision to admit the person into RACF was not the end of the care giving, rather the carer's role was transformed from home based carer to a carer in the RACF. Carers continued to be concerned about the older person now in RACF, they did not relinquish care but felt they had no other option but to place the person in RACF as there was inadequate support to maintain the older person at home.

Illustrations of data supporting the findings informing this category:

"While he's there I want to be there with him as much as I can".^{41(p173)}

"I make her special meals, take them to the home, and leave them in the fridge".^{33(p37)}

"He was bough here from the hospital. He was never home again. It was a terrible shock, a terrible shock. I could never take him home again."^{10(p1191)}

Category 2.2: *Separation is often sudden, carers may experience feelings of loneliness, sadness, disillusionment and have difficulty in adjusting to their changed relationship with the person and their sense of identity.*

There were 14 findings that informed this category. They revealed that spousal carers with a history of living together felt the emotional, psychological, financial and practical adaptation to changes in their living arrangements, and their social and personal identity. Spousal carers also had difficulty adjusting to how much time to allow for themselves following the admission of the person to the RACF, whereas adult children expected a period of adjustment, and reassured themselves that the person in RACF would adjust. Those who were in poor health themselves felt insecure and uncertain of their own future.

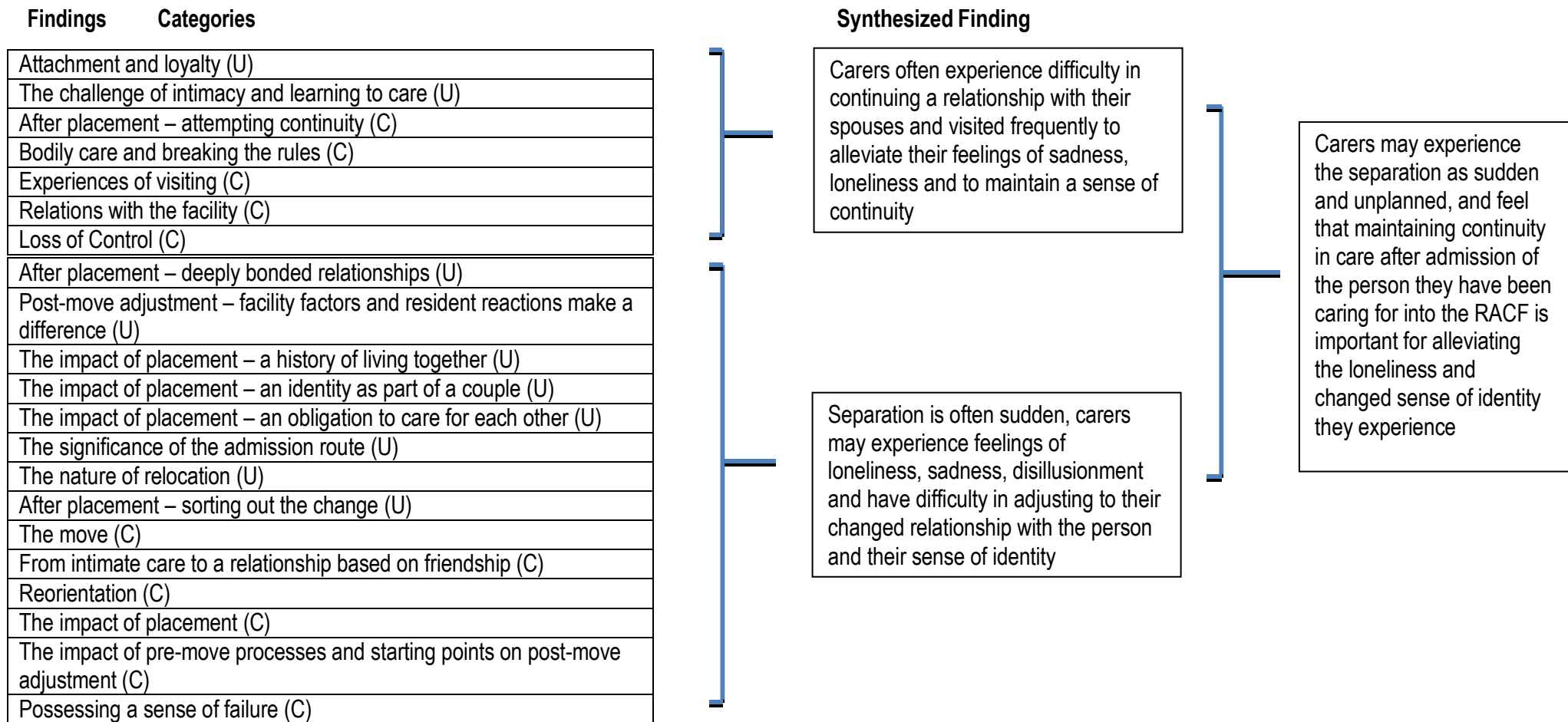
The findings reveal that when admission into a RACF occurred it was often very quick due to bed availability at a RACF. Carers often experienced distress at the sudden and unplanned separation from their partner. Carers often felt intense emotions on leaving the older person at the RACF as well as on return to their residence brought on by the realization that the older person would never be home again. This was evident both when the older person was admitted directly from hospital or from their home. Some carers saw an improvement in the older person's state after a period of time in the RACF which assisted in their adjustment and acceptance of the decision to admit the person.

Illustrations of data underpinning the findings in this category:

".. it felt hard...and then when I got home and thought of it ...'he will never be home again and we have a double bed in there and I will have to lay there on my own ..' we have been married so many years..."^{35(p1182)}

"I'm afraid of what people will say of me since I've bought my parents over here".^{38(p353)}

Figure 4. Meta-aggregative synthesis summary for synthesized finding 2: Sudden separation and a desire for continued relationship



3.2.3. Synthesized finding 3 (Figure 5)

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.

The third synthesized finding was derived from two categories underpinned by a total of 18 findings. Below, a summary of each of the two categories is provided together with a few key illustrations that support them.

Category 3.1: Carers are better able to adjust and accept nursing home placement when they are familiar with the RACF

There were seven findings that informed this category. The findings showed that carers were able to accept the transition in a more positive light if they themselves knew some of the staff in the RACF in which the person they had been caring for had been admitted. Knowing other residents and staff working in the RACF was important to carers. Carers also felt reassured about the admission when they knew that the older person had a preference for a RACF. When there was a sense of familiarity with the RACF carers felt more positive about the decision to admit the person and maintain a sense of control about the move. Many were planning on maintaining continuity and visiting after admission. Living nearby and being aware of other family and friends in the RACF assisted carers to adjust to the move and enabled continuity of relationships.

The findings indicated that with some pre-planning prior to the person being admitted into the RACF and having a sense of familiarity with the RACF assisted carers accept and adjust post-move to the older person in residential care.

Illustrations of data supporting the findings informing this category:

"I decided I wanted him go to 'The Limes because it is a good nursing home. I had a look about it. The 'Limes' is a nice home and it was comfortable and there were people in

it he did know. He had cousins even working in it".^{29(p6)}

"When my mother was admitted and I looked around and I seen (sic) five people she would have known as residents who were in that home. I knew one of the nurses that I worked with previously in the hospital. It was a big help".^{30(p11)}

Category 3.2: *Administrative processes often take precedence over emotional and psycho-social needs of carers during the admission of an elderly person into a RACF with the emphasis on admitting the person, not on developing a continuing relationship, which makes the experience more traumatic.*

A total of 11 findings described this aspect of the carers' experience of feeling a lack of control over the processes and the admission of the person to a RACF. This was partly because there was frequently no real choice about which RACF the person would be going to, as it was predominantly determined by availability at the time of need, and when the shift occurred it was sudden. Carers perceived that the administrative demands were inflexible and outweighed any emotional support to carers.

Carers were often told that they could be on a waiting list at a RACF for years. Yet when a RACF bed became available, either from hospital or their home, paperwork was required very quickly and the person could be admitted within 24 hours. Carers felt they had no control over this, as they were told they had to accept the first available RACF if the person was in hospital at the time or if they were still living in the community. If they did not accept that bed at that time they would be placed further down the waiting list.

With respect to transfers direct from hospital, many carers indicated that others took control and validated the decision and the need for admission to a RACF. Whilst some carers experienced separation anxiety, another study indicated the transfer to RACF from hospital to be less traumatic than the move direct from home, as the first stage of separation had already begun.

The findings indicated that when communications and information are forthcoming from the RACF it assisted carer's adjustment post-move compared to when minimal support or information was provided at the time of admission. The findings also indicated

that negative experiences pre-move impacted on carers' post-move adjustment and acceptance.

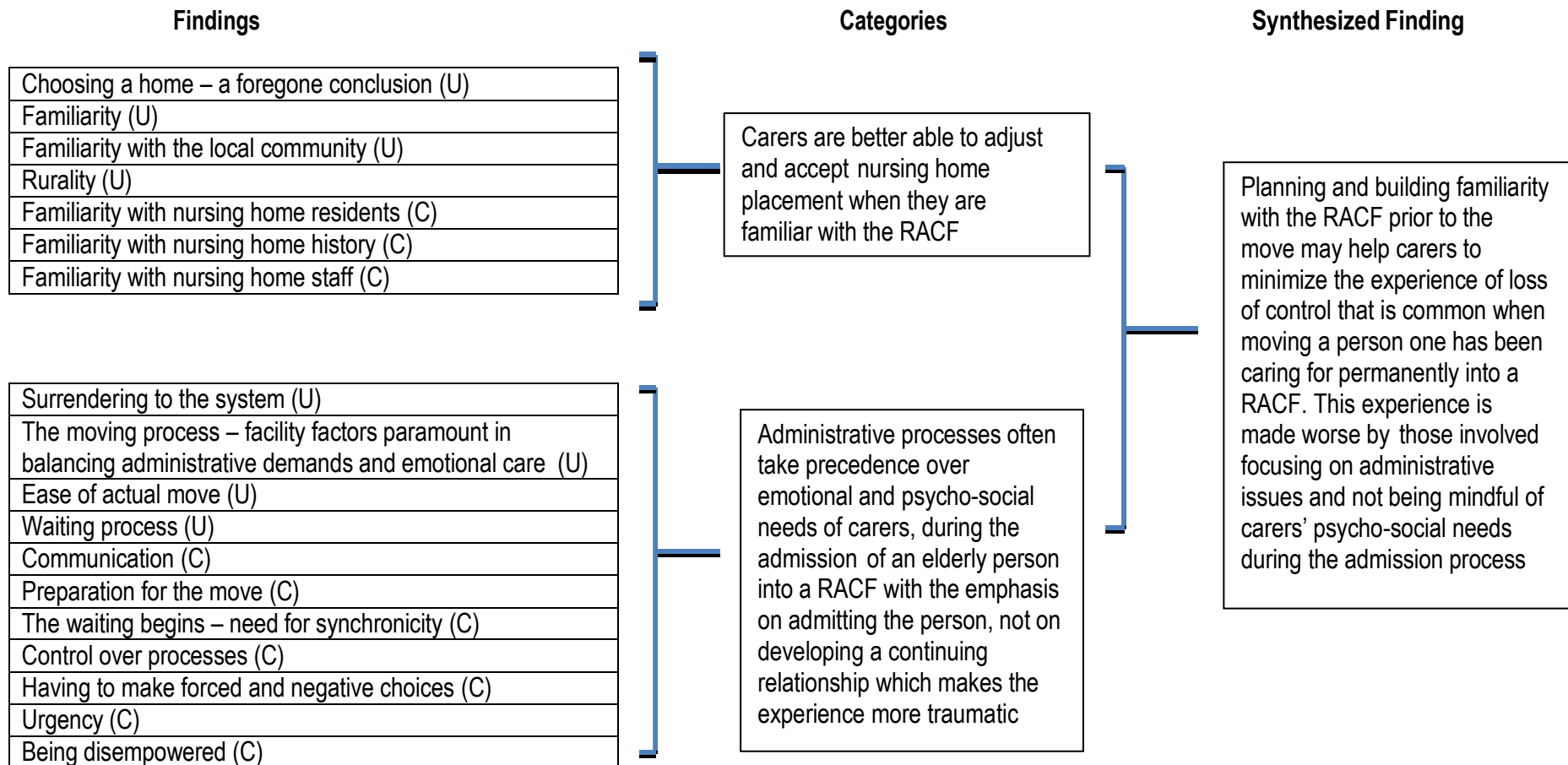
Illustrations of data supporting the findings informing this category:

"That was the most frustrating part, not knowing if it was two months or two years". 39(p26)

"They wanted her (at the facility) by ten. I said "little old ladies don't get up, have breakfast, get dressed and get anywhere by ten, on top of an-hour-and-a-half driving". They were pretty firm about (it); that's the time we do admissions".39(p29)

"He was brought here from the hospital. He was never home again. It was a terrible shock, a terrible shock. I could never take him home again".10(p1191)

Figure 5. Meta-aggregative synthesis summary for synthesized finding 3: Familiarity with a RACF and the impact of processes associated with the transition.



Chapter 4 – Discussion

4.1 Summary of the review findings and their significance

The systematic review identified and included 14 qualitative studies, all of good methodological quality, that have addressed the question about carers' experiences when the person they have been caring for is admitted into a RACF with the understanding that it is permanent. The included studies together provided a rich and relatively large body of evidence that was then analysed and synthesized to address the question. More specifically, a total of 71 findings about carers' experiences were extracted from the studies, which were organized into seven categories based on similarity of meaning and then subsequently aggregated into three synthesized findings, each describing a different key feature or element of the multi-dimensional and complex experience that emerged from the existing qualitative studies. The essence of the experience captured in each of the three synthesized findings is summarized briefly below.

4.1.1. The first synthesized finding - Carers' mixed feelings, crisis and need for support:

With respect to this first main aspect of the experience, the qualitative evidence identified and included in this review indicated that carers experience mixed feelings, with guilt emerging as the most prominent feeling. The evidence shows that the time of admission of the elderly person into a RACF was often preceded by a crisis and the final part of the experience in synthesized finding one is the feeling of a need for validation and support.

4.1.2. The second synthesized finding - Sudden separation and a desire for continued relationship:

Synthesized finding two provides evidence on the loneliness many carers may experience after the sudden separation from the person they have been caring for and have a desire for their relationship to continue. The evidence shows that visiting the RACF emerged as a means of maintaining carers' identity as a spouse as well as avoiding feelings of loneliness.

4.1.3. The third synthesized finding - Familiarity with a RACF and the impact of processes

associated with the transition:

The key features of the experience captured in synthesized finding three may be described as familiarity with the RACF pre-placement as a factor that eases carers' experiences, and assists carers' sense of control and sense of continuity. The evidence suggests that when carers have a sense of familiarity with the RACF they experience a more positive transition and acceptance when the person is admitted into the preferred RACF.

Reflecting on the findings, one noteworthy feature is that the experience of carers is typically multi-faceted, and commonly involves hardship for both the carer and the elderly person admitted to a RACF who often has become very frail and sick.

A recent systematic review that addressed a similar question to this review but focussed more narrowly on how carers experience a person with dementia transitioning into a RACF, had similar findings to this review. Its findings included "emotional concerns" of carers with respect to feelings of grief and shame about the decision, "knowledge information" with carers not understanding the care-system, and "support" indicating a need for counselling for carers during the care-transition period. It also indicated that support was needed, but what the support should be was not explicitly stated. Moreover, its findings suggested a need for programs to be designed and delivered in a continuous way, starting prior to admission and continuing thereafter.⁴³

Another important implication that emerged from the findings in this review is that carers' experiences may be different, depending on the actions they and the person they have been caring for have taken before the transition. Carers' experiences may be more positive with familiarisation of a RACF and pre-planning with the older person. This inference, which is positive and significant from a support/intervention perspective, emerged from the evidence showing that planning for a RACF admission, and becoming familiar with the RACF before the move improves the transition experience.

On a less positive note, the findings highlight how difficult the separation may be for carers and people admitted in the RACF, especially those who are particularly vulnerable, for example those with dementia and/or declining physical mobility and functioning.

Previous studies not included in this review due to not meeting the inclusion criteria as carers before admission to a RACF have suggested that family carers experiences may be able to be enhanced if they are able to work in partnership with RACF staff.^{11,12,13} This is noteworthy for further research based on the findings in this review.

A point missing from the studies and unable to infer was whether carers' experiences changed over the period of time as a result of the older person's admission to RACF. Data was collected at differing periods of time, that being prior to the move, post-move and up to three and a half years after admission. It is unknown whether carers' experiences changed over the period of time from immediately preceding the admission to RACF or within a short-time frame after the person's admission. Further research detailing this information would assist in being able to identify and implement appropriate support at appropriate times across the continuum from pre-move, during the transition and post-move and or ongoing thereafter.

A major theme that emerged from the evidence, and was reflected in all three synthesized findings, is that carers commonly feel alone and not in control and therefore could benefit from support and validation of their decision. The multi-faceted and complex experiences of carers, shown by their mixed and often conflicting emotions, including guilt, sense of failure, relief, loss and sadness, may be exacerbated by the events they cannot control, such as declining health. Carers' sense of loneliness may be exacerbated by the sudden loss of their companion and for some a loss of their identity as a couple. Thus visiting the RACF may not only provide a sense of continuity but also a level of support. Carers may also feel a sense of reassurance having undertaken some pre-planning with the older person and becoming familiar with the preferred RACF.

Whilst the findings in this systematic review highlight the need for carers to be provided with support, and suggest that measures are required to support carers, they reveal nothing about what kind of support measures carers found most meaningful/valuable for improving their well-being or why.

4.2. Knowledge Gaps

The review highlighted a number of knowledge gaps in the qualitative evidence base regarding how carers experience the transition to a RACF. First in this regard is the gap in the evidence base on what support is provided by organizations and RACFs to carers pre-move and how carers experience the support – is it beneficial or not? Ascertaining what the evidence – both qualitative and quantitative suggests about the most appropriate and effective support measures for carers is important to inform future practices, programs and policies.

Secondly, there is a lack of knowledge about the different sub-groups of carers, and if their need for support differs. There were insufficient data in this review to undertake sub-group analysis and the question of differences in experiences was not specifically identified. However, it is important from a policy and practice perspective. There is a need to understand and describe different carer cohort experiences, including differences by age, gender, those in same sex-relationships, ethnicity/culture as well as those with varying amounts of financial security. A particular knowledge gap in the context of the aged care reform agenda in Australia is the studies on how Aboriginal and Torres Strait Islander carers experience moving someone they have been caring for into a RACF. The review did not identify anyone as Aboriginal or Torres Strait Islander background, nor if anyone was under 65 years of age and admitted to a RACF with an age related condition. This information is important, as RACF do not specifically cater for younger people. In addition, lack of understanding about how the carer's experience differs depending on the length of time providing care prior to the move to RACF is another knowledge gap. The length of time providing care to the person in their home before them being moved into a RACF was not identified in all studies. This would have been relevant information to obtain as carers often cited exhaustion as a pre-cursor to not coping and, in turn, to the move into a RACF. Furthermore there was minimal information on services provided in the home before admission to the RACF. Having this knowledge may be beneficial to be able to increase appropriate levels of support and services prior to reaching a crisis point.

4.3. Limitations

The understanding of carers' experiences when the person they have been caring for has

been admitted into a RACF permanently generated by this review was based on qualitative evidence from a relatively narrow range of countries. The English language limitation meant that studies published in other languages (if they exist) will have been missed. In addition whilst the intention of this review was to draw evidence from a large number of developed countries, only studies from six countries, namely Australia, Canada, United Kingdom (UK), Sweden, Korea and the United States (US) were identified. Of the 14 studies, 12 were conducted in metropolitan and urban areas and only two in rural/remote areas (of which those two were drawn from the same study). This limited country coverage and concentration of studies in metropolitan areas is important for appropriate understanding of how the findings may be generalized.

A second limitation relates to the time frame of data collection in the studies, and differences across studies in this regard. Interviews of the carers were undertaken at varying stages of the transition and admission to a RACF. Some carers were interviewed prior to admission to a RACF once the person's name was on the waiting list. Other carers were interviewed in hospital waiting for a RACF bed while others were interviewed soon after admission to the RACF. Other carers were interviewed at various stages and up to three and half years after RACF admission. This is relevant as people's experiences may have changed over time.

This review included studies reporting the experiences of relatives for which the relatives were explicitly identified as carers to the person before admission into a RACF. Some relatives may have been de facto carers but not identified as such, and hence by excluding these studies we may have excluded perspective/experience of which would have been relevant, and could have offered novel insights.

4.4. Recommendations for practice

The findings in this review suggest that

- Carers be encouraged to plan early for the eventuality of the care receiver being admitted into a RACF and develop a sense of familiarity with the selected RACF before the transition (Grade B);
- Carers and the person they are caring be provided with information from aged care service providers about the specific RACF the person is moving to (Grade B);

- Health care professionals, including social workers and other clinicians/aged care workers, to assess the needs of carers at the time of transition, and refer carers to relevant support programs (Grade B);
- Where feasible strategies to facilitate continuity in the relationship/of care be implemented at the RACF in consultation with the carer at the time the person enters into the RACF (Grade B).

4.5. Recommendations for Research

Whilst a substantial amount of research on the effectiveness of support interventions for carers in different areas has been undertaken, there is a need for further qualitative and quantitative studies to develop an evidence-based understanding of the most effective, appropriate and feasible support interventions for carers. This research must consider needs of different groups, for example females compared to males, carers of different ages, and carers from different cultural and language groups.

A systematic review of mixed evidence, addressing the question of the most appropriate, effective and cost effective support interventions for carers prior to the transfer, during the transition to a RACF and following admission would be useful to inform programs and practice.

Given that carers in this review identified negative experiences when transitioning directly from hospital, further primary research is required at the point of crisis when a person is hospitalized.

- Within Australian, New South Wales Hospitals there has been an initiative of employing Acute to Aged Care Related Services (AARCS) workers as designated staff to assist patients and their families or carers transition a patient direct from hospital to a RACF. It may be timely if a mixed method study design be conducted to understand the effectiveness of AARCS intervention in supporting and providing information to carers and/or significant others and their experiences pre-move and during the transition to a RACF.
- Similarly, a mixed method study design could be conducted in other hospitals in developed countries to understand what interventions are in place to support carers and/or significant others in their experiences of support pre-move and during the

transition to a RACF.

Additional qualitative research at point of entry of the new resident to the RACF may be useful to understand carers' psycho-social needs at and following admission. This information may inform and assist in the promotion of steps that enable a continuing caring relationship and partnership after RACF separation.

4.6. Conclusion

The synthesized findings about the nature of the carer's experiences signals the importance of carers being provided with support prior to admission of the older person into a RACF, during the transition, and following admission. The review shows that carers, both male and female, experience mixed feelings and difficulties, and often want to continue being involved in the older person's care after they have been admitted into a RACF. The findings indicate that carer experiences may be enhanced and their stress eased by careful planning prior to the move. Building familiarity with the RACF prior to the move also emerged as important for its potential to assist carers in adjusting to the separation and promoting continuity in the relationship. The review points towards directions for future research. It also supports a number of recommendations for practice.

Conflict of Interest

None Known

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Appendices

Appendix I: Search strategy

PubMed	<p>(Caregivers[mh] OR caregiver*[tw] OR Carer*[tw] OR care giver[tw] OR family[mh:noexp] OR adult children[mh] OR spouses[mh] OR spouse*[tw] OR wife[tw] OR wives[tw] OR husband*[tw] OR partner[tw] OR partners[tw] OR family[tw] OR families[tw])</p> <p>AND</p> <p>((Stress, psychological[mh:noexp] OR experience*[tw] OR emotions[mh] OR emotion*[tw] OR adaptation, psychological[mh:noexp] OR coping behaviour[tw] OR guilt[tw] OR psychology[sh] OR psychology[tw] OR life change events[mh] OR life change event[tw] OR financial burden[tw] OR Qualitative research[mh] OR qualitative[tw]) AND (institutionalization[mh:noexp] OR institutionalis*[tw] OR permanent placement[tw] OR relocation*[tw] OR transition[tw] OR transition*[tw] OR relinquish*[tw] OR placement[tw] OR nursing home entry[tw] OR nursing home placement[tw] OR daily life[tw] OR change process[tw]))</p> <p>AND</p> <p>(Long term care[mh] OR long term care[tw] OR residential facilities[mh] OR residential facility[tw] OR nursing homes[mh] OR nursing home*[tw] OR assisted living facilities[mh] OR geriatric nursing[mh] OR geriatric nursing[tw] OR homes for the aged[mh] OR old age home[tw])</p> <p>Limits: English and humans</p>
CINAHL	<p>(TI Caregiver OR TI Caregivers OR (TI"Care giver") OR AB caregiver OR AB caregivers OR (AB"care giver") OR TX Caregiver or TX caregivers OR (TX"care giver") OR (TX "care givers") OR TX carer OR TX carers OR MH Family+ OR TX family OR (TX"adult child") OR (TX"adult children") OR TX spouses OR TX spouse)</p> <p>AND</p>

((MH"Stress,Psychological+" OR TX experience OR TX experiences OR TX emotion OR TX emotions OR TX adaptation OR TX coping OR (TX"coping behaviour") OR TX guilt OR psychology OR (TX"life change event") OR (TX"financial burden")) AND (MM"Institutionalization+" OR TX institution OR TX institutions OR (TX"permanent placement") OR TX relocation OR TX transition OR TX transitions OR TX relinquish OR TX placement OR (TX"nursing home entry") OR (TI"Nursing Home Placement") OR (AB"nursing home placement") OR TX placement OR (TX"daily life") OR (TX"change process"))

AND

((MM"long term care/PF") OR (TX"residential facility") OR (TX"residential facilities") OR (TI"Nursing Home*") OR (AB"Nursing Home*") OR (MM"nursing homes+") OR (TX"nursing home") OR (TX"nursing homes") OR (TX"assisted living facility") OR (TX"assisted living facilities") OR (TX"geriatric nursing") OR (TX"old age home") OR (TX"old age homes"))

AND

(TX qualitative OR (TX"qualitative research") OR TI qualitative OR (AB"qualitative research"))

Limits: English, academic journals, ages inc adolescents, humans

PsycINFO

(Caregiver or caregivers or care giver or care givers or carer or carers or family or adult child or adult children or spouses or spouse or wife or wives or husband or husbands or partner or partners or families)

AND

((stress or psychological or experience or experiences or emotion or emotions or adaptation or coping or coping behaviour or guilt or psychology or life change event or financial burden or qualitative research or qualitative) AND (institutionalization or institution or institutions or permanent placement or relocation or transition or transitions or relinquish or placement or nursing home entry or nursing home placement or daily life or change process))

AND

(long term care or residential facility or residential facilities or nursing home or nursing homes or assisted living facility or assisted living facilities or geriatric nursing or old age home or old age homes)

Limits: English and Humans

SCOPUS

((caregiver OR caregivers OR "care giver" OR "care givers" OR carer OR carers OR family OR "adult child" OR children OR spouses OR spouse OR wife OR wives OR husband OR husbands OR partner OR partners OR families))

AND

((stress OR psychological OR experience OR experiences OR emotion OR emotions OR adaptation OR coping OR "coping behaviour" OR guilt OR psychology OR "life change event" OR "financial burden" OR "qualitative research" OR qualitative) AND (institutionalization OR institution OR institutions OR "permanent placement" OR relocation OR transition OR transitions OR relinquish OR placement OR "nursing home entry" OR "nursing home placement" OR "daily life" OR "change process"))

AND

("long term care" OR "residential facility" OR "residential facilities" OR "nursing home" OR "nursing homes" OR "assisted living facility" OR "assisted living facilities" OR "geriatric nursing" OR "old age home" OR "old age homes"))

Limits: English

EMBASE

((caregiver OR caregivers OR "care giver" OR "care givers" OR carer OR carers OR family OR "adult child" OR children OR spouses OR spouse OR wife OR wives OR husband OR husbands OR partner OR partners OR families))

AND

((stress OR psychological OR experience OR experiences OR emotion OR emotions OR adaptation OR coping OR "coping behaviour" OR guilt OR psychology OR "life change event" OR "financial burden" OR "qualitative research" OR qualitative) AND (institutionalization OR institution OR institutions OR "permanent placement" OR relocation OR transition OR transitions OR relinquish OR placement OR "nursing home entry" OR "nursing home placement" OR "daily life" OR "change process"))

AND

("long term care" OR "residential facility" OR "residential facilities" OR "nursing home" OR "nursing homes" OR "assisted living facility" OR "assisted living facilities" OR "geriatric nursing" OR "old age home" OR "old age homes"))

Limits: English

Unpublished studies

MedNar Caregivers AND experiences AND relocation AND "nursing home" AND qualitative

ProQuest Dissertations & Thesis A&I

Caregivers AND experiences AND relocation AND "nursing home" AND qualitative

Limits: English

Google Scholar Caregivers AND experiences AND relocation AND "nursing home" AND qualitative

Limits: English

AIHW site.aihw.gov

Department of Health and Ageing

Appendix II: JBI QARI Critical Appraisal Checklist

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

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

Overall appraisal: Include Exclude Seek further info.

Comments (including reason for exclusion)

Appendix III: JBI QARI data extraction instrument

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

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Method

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Phenomena of interest

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Setting

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Geographical

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Cultural

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Participants

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Data analysis

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Authors Conclusions

.....

Comments

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Complete

Yes

No

Appendix IV: Studies excluded at full text examination and critical appraisal with reasons

Alice Lau W, Lotus Shyu Y, Lin L, Yang P. Institutionalized elders with dementia: Collaboration between family caregivers and nursing home staff in Taiwan. *J Clin Nurs*. 2008;17(4):482-90.

Reason for exclusion: Did not meet phenomena of interest - focus was on partnership processes.

Ayalon L, Green V. Grief in the initial adjustment process to the continuing care retirement community. *J Aging Stud*. 2012;26(4):394-400.

Reason for exclusion: Did not meet participant type - as not identified as carers before nursing home admission.

Bern-Klug M. The Emotional Context Facing Nursing Home Residents' Families: A Call for Role Reinforcement Strategies from Nursing Homes and the Community. *J Am Med Dir Ass*. 2008;9(1):36-44.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Bernoeth M, Dietsch E, Davies C. Forced into exile: The traumatising impact of rural aged care service inaccessibility. *Rural Remote Health* .2012; 12(1) 1-8.

Reason for exclusion: Did not meet participant type - unclear if relatives were carers before nursing home admission.

Bramble M, Moyle W, McAllister M. Seeking connection: family care experiences following long-term dementia care placement. *J Clin Nurs*.2009; 18(22): 3118-3125.

Reason for exclusion: Did not meet participant type - unclear if relatives were carers before nursing home admission.

Browne V. The lived experience of men and women who have placed a spouse with Alzheimer's disease in a nursing home. *Dissertation Abstracts International: Section B: The Sciences and Engineering*. 2002;63(2-B):735.

Reason for exclusion: Not qualitative in study design.

Cheek J, Ballantyne A. Coping with crisis: how Australian families search for and select an aged care facility for a family member upon discharge from an acute care setting. *Contemp Nurse*. 2001;10(1/2):12-20.

Reason for exclusion: Not qualitative in study design.

Davies S. Meleis's theory of nursing transitions and relatives' experiences of nursing home entry *J Adv Nurs*. 2005;52(6):658-71.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Davies S, Nolan M. Making the best of things': Relatives' experiences of decisions

about care-home entry. Ageing Society .2003; 23(4): 429-450.

Reason for exclusion: Did not meet participant type - unclear if all were carers before nursing home admission.

Davies S, Nolan M. Making the move': Relatives' experiences of the transition to a care home. Health Soc Care.2004; 12(6): 517-528.

Reason for exclusion: Did not meet participant type - unclear if all were carers before nursing home admission.

Davies S, Nolan M. 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. Int J Nurs Stud. 2006;43(3):281-91.

Reason for exclusion: Did not meet participant type - unclear if all were carers before nursing home admission.

Fleming A. Family caregiving of older people with dementing illnesses in nursing homes: A lifeline of special care. Australas J Ageing. 1998;17(3):140-4.

Reason for exclusion: Did not meet participant type – unclear if all identified as carers before nursing home admission.

Ford G. Life after placement: experiences of older rural caregivers after placing a family member into residential care. Rural Remote Health. 2008;8(3):1030.

Reason for exclusion: Did not meet participant type – unclear if all identified as carers before nursing home admission.

Garity J. Caring for a family member with Alzheimer's disease: Coping with caregiver burden post-nursing home placement. J Gerontol Nurs 2006;32(6):39- 48.

Reason for exclusion: Did not meet participant type – unclear if all identified as carers before nursing home admission.

Givens J, Lopez R, Mazor K, Mitchell S. Sources of stress for family members of nursing home residents with advanced dementia. Alzheimer Dis Assoc Disord. 2012;26(3):254-9.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Johnson M, Werner C. "We had no choice". A study in familial guilt feelings surrounding nursing home care. J Gerontol Nurs. 1982;8(11):641-5, 54.

Reason for exclusion: Did not meet participant type – as did not identify as carer before nursing home admission.

Judd R. The stress of care giving: Factors impacting family caregivers following entry of the care recipient into a nursing home. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2009;69(8-A):3320.

Reason for exclusion: Not qualitative in study design.

Kavanaugh K. Easing the transition for new residents ... and for their families. Balance (Alexandria, Va). 1997;1(2):16-7, 34, 44.

Reason for exclusion: Not qualitative in study design.

Keefe J, Fancey P. The care continues: Responsibility for elderly relatives before and

after admission to a long term care facility. *Fam Relat.* 2000;49(3):235-44.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Kellett U. Meaning-making for family carers in nursing homes. *Int J Nurs Prac.* 1998;4(2):113-9.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Kellett U. Searching for new possibilities to care: A qualitative analysis of family caring involvement in nursing homes. *Nursing Inquiry.* 1999;6(1):9-16.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Kellett U. Seizing possibilities for positive family caregiving in nursing homes. *J Clin Nurs.* 2007;16(8):1479-87.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Kellett U. Bound within the limits: Facing constraints to family caring in nursing homes. *Int J Nurs Prac.* 2000;6(6):317-23.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Kelsey S. Dementia and transitioning from assisted living: Administrators' and caregivers' perspectives. *Dissertation Abstracts International Section A: Humanities and Social Sciences.* 2009;70(3-A):981.

Reason for exclusion: Not qualitative in study design.

Kelsey S, Laditka S, Laditka J. Caregiver perspectives on transitions to assisted living and memory care. *Am J Alzheimers Dis Other Demen.* 2010;25(3):255-64.

Reason for exclusion: Did not meet participant type – as not all identified as carers before nursing home admission.

Kemp C. Married Couples in Assisted Living: Adult Children's Experiences Providing Support. *J Fam Issues.* 2012;33(5):639-61.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Kinsman J. Guilt in caregivers of persons with dementia: Pre and post nursing home placement. *Dissertation Abstracts International.* 1993;53(12-B):6223.

Reason for exclusion: Thesis not able to be retrieved.

Kong E, Deatrick J, Evans L. The experiences of Korean immigrant caregivers of non-English-speaking older relatives with dementia in American nursing homes. *Qual Health Res.* 2010;20(3):319-29. Epub 2009/11/27.

Reason for exclusion: Did not meet participant type – as not identified as carers before

nursing home admission.

Krause AM, Grant LD, Long BC. Sources of stress reported by daughters of nursing home residents. *J of Aging Stud.* 1999;13(3):349-64.

Reason for exclusion: Did not meet participant type – unclear if carers before nursing home admission.

Krull A. Health Care Professionals, Friends, Family, and God: Interactions Contributing to Caregivers' Long-Term Care Decisions. *Sociological Spectrum* .2013; 33(4): 329-340.

Reason for exclusion: Did not meet phenomena of interest - focused on activities not experiences.

Legault A, Ducharme F. Advocating for a parent with dementia in a long-term care facility: The process experienced by daughters. *J Fam Nurs.* 2009;15(2):198-219.

Reason for exclusion: Did not meet participant type – as not identified as carers before nursing home admission.

Levine C, Halper D, Peist A, Gould D. Bridging troubled waters: family caregivers, transitions, and long-term care. *Health affairs (Project Hope).* 2010;29(1):116-24. Epub 2010/01/06.

Reason for exclusion: Not qualitative in study design.

Lewis M, Hepburn K, Narayan S, Lally R, Corcoran-Perry S, Maddox M, Dropkin K, Hasse S. Decision- making by family caregivers of elders experiencing dementia. *Am J Alzheimers Dis.* 2000;15(6):361-6.

Reason for exclusion: Did not meet participant type – unclear if carers before nursing home admission.

Lichtenberg P. Assisting Urban Caregivers After Nursing Home Placement: Results from Two Preliminary Programs. *Clin Gerontol.* 2007;30(2):65-77.

Reason for exclusion: Not qualitative in study design.

Liken M. Caregivers in crisis: Moving a relative with Alzheimer's to assisted living. *Clin Nurs Res.* 2001;10(1):52-68.

Reason for exclusion: Did not meet participant type – not identify as carers before nursing home admission.

Liken M. The experience of moving a relative with alzheimer's disease to an assisted living facility. *Dissertation Abstracts International: Section B: The Sciences and Engineering.* 1998;59(2-B):0604.

Reason for exclusion: Thesis not able to be retrieved.

Lloyd D. Crisis placement of the elderly in nursing homes: a qualitative study of the lived experience of primary caregivers. *Perspectives CGNA.* 2010;34(2):13-21.

Reason for exclusion: Not qualitative in study design.

Mackenzie P, MacLean M. Altered roles: The meaning of placement for the spouse who remains in the community. *J Gerontol Soc Work*. 1992;19(2):107-20.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Majerovitz S, Mollott R, Rudder C. We're on the same side: Improving communication between nursing home and family. *J Health Commun*. 2009;24(1):12-20.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Marquis R, Freegard H, Hoogland L. Influences on positive family involvement in aged care: an ethnographic view. *Contemp Nurse*. 2004; 16(3): 178-186.

Reason for exclusion: Did not meet participant type - unclear if all identified as carers before nursing home admission.

Martin L, Miranda B, Bean M. An exploration of spousal separation and adaptation to long-term disability: Six elderly couples engaged in a horticultural programme. *Occup Ther Int*. 2008;15(1):45-55.

Reason for exclusion: Did not meet phenomena of interest – focus was on activities not experiences.

Meacham C, Brandriet L. The response of family and residents to long-term care placement. *Clin Gerontol*: 1997;18(1):63-7.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Nay R. Relatives' experiences of nursing home life: Characterised by tension. *Aust J Ageing*. 1997;16(1):24-9.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Nolan M, Dellasega C. 'It's not the same as him being at home': creating caring partnerships following nursing home placement. *J Clin Nurs*. 1999;8(6):723-30.

Reason for exclusion: Did not meet phenomena of interest, focus on processes.

Nolan M, Dellasega C. 'I really feel I've let him down': Supporting family carers during long-term care placement for elders. *J Adv Nurs*. 2000;31(4):759-67.

Reason for exclusion: Did not meet phenomena of interest, focus on processes.

Palmer J. Caregivers' experiences before and during the first year of nursing home placement of a family member with Alzheimer's disease. *Dissertation Abstracts International: Section B: The Sciences and Engineering*. 2010;70(10-B):6116.

Reason for exclusion: Thesis not able to be retrieved.

Paun O, Farran C. Chronic grief management for dementia caregivers in transition: intervention development and implementation. *J Gerontol Nurs*. 2011;37(12):28-35.

Reason for exclusion: Not qualitative in study design.

Paun O, Farran CJ. Nursing home placement of persons with Alzheimer's disease. *Alzheimer's Care Quarterly*. 2006;7(2):104-14.

Reason for exclusion: Not qualitative in study design.

Pearson A, Nay R, Taylor B. Relatives' experience of nursing home admissions: Preliminary study. *Aust J Ageing*. 2004;23(2):86-90.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Penrod J, Dellasega C. Caregivers' perspectives of placement: implications for practice. *J Gerontol Nurs*. 2001;27(11):28-36; quiz 54-5.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Reed J, Morgan D. Discharging older people from hospital to care homes: Implications for nursing. *J Adv Nurs*. 1999;29(4):819-25.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Reisman B. Adjusting to a residential facility for older persons: A child's perspective. *J Gerontol Soc Work*. 1985;9(2):91-100.

Reason for exclusion: Not qualitative in study design.

Riddick C, Cohen-Mansfield J, Fleshner E, Kraft G. Caregiver adaptations to having a relative with dementia admitted to a nursing home. *J Gerontol Soc Work*. 1992;19(1):51-76.

Reason for exclusion: Not qualitative in study design.

Rodgers B. Family members' experiences with the nursing home placement of an older adult. *Appl Nurs Res*. 1997;10(2):57-63.

Reason for exclusion: Did not meet participant type – as did not identify as carers before nursing home admission.

Rogers W. Psychological well-being of family caregivers of dementia patients in nursing homes. *Dissertation Abstracts International: Section B: The Sciences and Engineering*. 2000;60(9-B):4524.

Reason for exclusion: Thesis not able to be retrieved.

Rosenthal C, Dawson P. Wives of institutionalized elderly men: The first stage of the transition to quasi-widowhood. *J Aging Health*. 1991;3(3):315-34.

Reason for exclusion: Not qualitative in study design.

Sandberg J, Lundh U, Nolan M. Placing a spouse in a care home: the importance of keeping. *J Clin Nurs*. 2001; 10(3): 406-416.

Reason for exclusion: Did not meet participant type - unclear if all identified as carers before nursing home admission.

Schofield V. Rituals of visiting people with dementia in residential care. *Australas J Ageing*. 2001;20(4):187-91.

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Reason for exclusion: Did not meet participant type – not all identified as carers before nursing home admission.

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Reason for exclusion: Not qualitative in study design.

Appendix V: List of study findings

Findings for: Eriksson, H. and J. Sandberg - International Journal of Older People Nursing (2008); Transitions in men's caring identities: Experiences from home-based care to nursing home placement⁴³

Finding1	The challenge of intimacy and learning to care (U)
Illustration	The worse was ... you know when she wet her pants ... I noticed that as soon as she was upset, it would happen ... I changed her incontinence pads as often as four times a day and washed her and made her comfortable. Pg 133
Finding2	Bodily care and breaking the rules (C)
Illustration	Since I was alone giving her a shower bath was a hard task for me ... even if she didn't weigh that much she was still hard to move around. Pg 134
Finding3	From intimate care to a relationship based on friendship (C)
Illustration	You can say it's like a divorce where you still see each other, we don't live together and I can't even bring her home. Pg 135

Findings for: Kellett, U. M. - Journal of Advanced Nursing (1999); Transition in care: Family carers' experience of nursing home placement⁴⁰

Finding1	Loss of Control (C)
Illustration	Oh yes, I mean every little thing that you can do makes you feel less useless I suppose. It's a terrible feeling. I think most of us hate to think that things are out of our control, you like to feel that you're in control of everything to do with your own and then things get taken out of your hands. It's important to be involved and have your say. Pg 1478
Finding2	Being disempowered (C)
Illustration	So I think I don't know who got the biggest shock my brother or me, he wasn't prepared for it. When the doctor got on the phone and called an ambulance - I'm getting an ambulance because you're going to hospital and Harold said "I can't go. I've got things to do here before I go" and he said "I'm sorry but I'm getting an ambulance anyway". So when the ambulance came he had a bit of an argument with them but finally he went. But I think that really and truly destroyed him... he just sort of went to pieces. He didn't cry but he was just I think he thought the whole world was dropping out of him and I felt so terribly guilty. Pg 1477
Finding3	Having to make forced and negative choices (C)
Illustration	They rang and said "there's the possibility of a place, do you want to be considered"; And we sort of said 'Oh'. Six months before we'd said no because they hadn't pushed and she was still enjoying being around and she had nursed [name of daughter] and she was doing grandmother things. We sat and said "well what do you think?" and we both felt sick at the thought of it. I was pregnant with [name of daughter]. and they said "look we think you should at least look at it, we think you should proceed with it;"... we feared if we said 'No' this time and then got to the point where we couldn't cope that we would have to take whatever we could get, not necessarily at [name of nursing home]. It was a risk and we decided we did not want to take that risk. Pg 1477
Finding4	Feeling guilt, sadness and relief simultaneously (C)
Illustration	He didn't cry but he was just I think he thought the whole world was dropping out of him and I felt so terribly guilty. Pg 1477

	You just couldn't go to the toilet, you couldn't answer the phone, he demanded to be fed 5 minutes after he had had his dinner. The way he was I had to keep an eye on everything. I had to put him into respite I needed sleep so badly... Anyway by the time the 3 weeks was up and I was to take him home I couldn't take him home ... he would just do anything anywhere, so you can see I couldn't have him. Pg 1477
Finding5	Possessing a sense of failure (C)
Illustration	The hard part was that mother had dementia so I was leaving her I felt with people who really did not understand dementia and I knew everything - you know I knew what mother liked and didn't like etc, and that was hard, not only the chest infection it was handing her over to people I felt at times, really didn't understand. If mother said a definite 'yes' they would believe that 'yes' you know, that's what mother did or had, but of course mother didn't. Pg 1476

Findings for: Kwon, S. H. and Y. S. Tae. - Asian Nursing Research (2012); Nursing home placement: The process of decision making and adaptation among adult children caregivers of demented parents in Korea⁴¹

Finding1	Realising a dead end (C)
Illustration	He used to leave the faucet running all night and peep into other's room at nights. Kids hated it ... and he used to curse at them so often. And one day, we found him washing his face with the water in the toilet. We were so shocked to see that (participant 14) .Pg 146
Finding2	Seeking a way out (C)
Illustration	I have to pay some money for her nursing home care, but for the most part, I think I could gain more because then I could have free time to myself, even though I have this heavy heart. But we couldn't just give up our whole life for her.. If you place your parent in a nursing home, you know that you lose one thing but also gain something (participant 16) Pg 147
Finding3	Accepting the inevitable decision (C)
Illustration	I believe that mother is now in good hands, much better than before. They provide good care with good food. But although the nurses are good to her, it wouldn't be the same as her being at home with her family around. She would miss her family and those contacts with us. That hurts me. And that makes me feel terribly guilty and uncomfortable. (participant 2) Pg 147
Finding4	Reorienting to changes (U)
Illustration	In the beginning, it felt like you abandoned your own baby when mother was admitted here. But I guess time heals even the most painful experiences like this. The people there always told us that it should be hard in the beginning but it would get better. I didn't believe it then, but as time passed, the pain waned. Time really heals (participant 8) pg 148

Findings for: Lundh, U., J. Sandberg, et al. - Journal of Advanced Nursing (2000); 'I don't have any other choice': Spouses' experiences of placing a partner in a care home for older people in Sweden⁴⁴

Finding1	Making the decision (C)
Illustration	... they told me, 'it is too difficult for you. You can't handle this yourself at home.' I didn't have the strength, although I did not complain but they understood. pg 1181

Finding2	The move (C)
Illustration	.. it felt hard...and then when I got home and thought of it ...'he will never be home again and we have a double bed in there and I will have to lay there on my own ..' we have been married so many years... pg1182
Finding3	Adjusting to the move (C)
Illustration	.. I am sure they do what they are supposed to .. clearly it's not like when he is with myself at home ... but it can't be, I realize that. Pg 1183
Finding4	Reorientation (C)
Illustration but I've said to myself that I have to live on, both for my husband and for our children and grandchildren... and for all our relatives who need me. But I have many difficult moments, I can tell you...many ...Pg 1183

Findings for: Park, M., H. K. Butcher, et al. - Research in Nursing and Health (2004); A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility⁴⁷

Finding1	Feeling exhausted (U)
Illustration	I've always told my sisters-in-law that things were too hard and asked them to help me. It would help my mind and body so much if they would lend their hand. I really would appreciate any help. My husband and I are both working so if somebody could come just once a month and give her a bath, it would be such a great help. I've said a lot about this to my sisters-in-law. They told me how sorry they were but since they all have their own family to care, it's all just talk. Pg 351
Finding2	Deep sorrow (U)
Illustration	When I arrived here with my mom, it was very heartbreaking to see all the doors and windows being locked with padlocks. pg 352
Finding3	Fractured relationships (U)
Illustration	My sisters-in-law and brothers-in-law opposed bringing my mother-in-law here. It was very hard to persuade them. They wouldn't listen to me, and the only thing they did was to blame me. Pg 352
Finding4	Apprehension (U)
Illustration	I'm afraid of what people will say of me since I've bought my parents over here. pg 353

Findings for: Penrod, J. and C. Dellasega. - Western Journal of Nursing Research (1998); Caregivers' Experiences in Making Placement Decisions⁴⁵

Finding1	Uncertainty (C)
Illustration	And only later did I ever think, ooh, we have other options. Maybe we should look at some of those other options and [I] had to worry about what those are and the financial parameters and that other stuff. pg 711
Finding2	Surrendering to the system (U)
Illustration	I was told that we had to fill out three applications... I turned it in to Social Services. Uh, that's pretty much it... other than that uh, I haven't done very much, you know. I've sort of waited for them to, they said there

	wasn't anything for me to do. So ... I just waited. pg 712
Finding3	Urgency (C)
Illustration	They made us rush around. They wanted everything down there. pg 715
Finding4	Validation of the experience (C)
Illustration	And she [social worker] said, it's a big job. And and again, she seemed from her body language, to be agreeing with like, oh, okay, I think - and you look for that sort of validation. You look for that, like have I made the right decision. pg 715

Findings for: Reuss, G. F., S. L. Dupuis, et al. - Journal of Gerontological Social Work (2005); Understanding the experience of moving a loved one to a long-term care facility: Family members' perspectives ⁴⁸

Finding1	Waiting Process (U)
Illustration	That was the most frustrating part, not knowing if it was two months or two years. pg 26
Finding2	Preparation for move (C)
Illustration	I wasn't happy with the move, I thought, and still think it happened too fast... there wasn't any time to think about it ... I found it happened too quickly. pg 26
Finding3	Control over process (C)
Illustration	I needed to see [the facility]. I was little taken aback, but I guess my feeling was that I'm in a hard place. If I didn't like it, and I said NO, then what else was there going to be? What was the point? You're off the list, unfortunately. pg 28
Finding4	Ease of actual move (U)
Illustration	They wanted her [at the facility] by ten. I said, "little old ladies don't get up, have breakfast, get dressed, and get anywhere by ten, on top of an-hour-and-a-half driving"... they were pretty firm about [it]; 'that's the time that we do admissions.' pg 29
Finding5	Communication (C)
Illustration	It is too bad you couldn't just deal with the Home itself... that whole process is too much red tape, too much bureaucracy, and you keep getting different case managers. You are always getting a machine. You never get a person. They are not there. They are only open from whatever [to] whatever... If I could just deal with the Home directly.. it would be so much easier. pg 31
Finding6	Support from others (U)
Illustration	If I didn't have two sisters, I don't know how we could do it. [One sister] basically looked after mom that moving day and [my other sister] and I and our husbands helped with the move and got a moving company. ..[that] was the only thing that helped that day, because it was such a stressful day. pg 32-33.
Finding7	Family/resident perceptions and attitudes towards placement (C)
Illustration	We were raised with the idea that you're supposed to look after your parents when they get old no matter what. And, for us to put him in an institution was very hard. The feeling of guilt is just huge. And a person can't shake it off. pg 34

Findings for: Ryan, A. and H. McKenna. - BMC Health Serv Res. (2013); 'Familiarity' as a key factor influencing rural family carers' experience of the nursing home placement of an older relative: a qualitative study³⁸

Finding1	Familiarity with the nursing home history (C)
Illustration	I went to school with Mrs Trusdale and I knew her from then. I knew that she was a good person. I knew it would be fine. (Interview 9) pg 4
Finding2	Familiarity with nursing home staff (C)
Illustration	The lady who lived next door to her used to look after her when we went on holiday. She actually worked in the nursing home for a while and that is another reason why we got her to that home. She would have a familiar face there as well. She would call with her (interview 15) pg 4
Finding3	Familiarity with nursing home residents (C)
Illustration	I used to take her to see a friend who moved into the home and loved it and said it was the best thing she had ever done going to 'The Glen' and because mum is vaguely familiar with it, thinking about the fact that she can't see perhaps that would be reassuring and it is very near. It only takes 10 minutes to get there. (Interview 2) pg 5
Finding4	Familiarity with the local community (U)
Illustration	I decided I wanted him to go to 'The Limes' because it is a good nursing home. I had a look about it. The 'Limes' is a nice home and it was comfortable and there were people in it he did know. He had cousins even working in it. (interview 28) pg 6

Findings for: Ryan, A., H. McKenna, et al. - Ageing and Society. (2012); Family care-giving and decisions about entry to care: A rural perspective³⁹

Finding1	No place like home (U)
Illustration	She always wanted to be at home. I would love her to stay at home but who is going to look after her. There is nobody. (R10) pg 8
Finding2	Carer Advocate (C)
Illustration	My doctor said to me that the rest of the family would be blamed for that because they walked away from it. I remember one time going to the doctor and asked for a tonic. I said I felt my patience and my nerves were totally shredded and she questioned me about it and said that it was totally unacceptable and that I couldn't go on. She didn't say it in so many words but I think she was saying that I would be heading for a nervous breakdown. (R18) pg 9
Finding3	Choosing a home: a foregone conclusion (U)
Illustration	My sister and I had actually chatted about that and mum had said one time to my sister that if she went to a nursing home she would like to go to the 'Elms'. In that respect it left it a little a bit easier for us in that we knew that if she was going to a nursing home that is where she had said. (R3) pg 10
Finding4	Rurality (U)
Illustration	A lot of people love the country and they see the silage being made up and the cows down the field. The girls bring them out for a walk in their wheelchairs or whatever when the weather is warmer. (R13) pg 10
Finding5	Familiarity (U)
Illustration	When my mother was admitted and I looked around and I seen five people she would have known as

	residents who were in that home. I knew one of the nurses that I worked with previously in the hospital...it was a big help. (R27) pg 11
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Findings for: Ryan A, Scullian H. - Journal of Advance Nursing (2000); Nursing home placement: an exploration of the experiences of family carers¹⁰

Finding1	Inability to cope (U)
Illustration	I was doing all I could and other people weren't. I was angry at that. I wasn't getting any support. I got about two hours a week from my sisters but I got no help from statutory services. pg 1191
Finding2	Health status (C)
Illustration	My sister would come over in the morning. She said you're going to end up with a nervous breakdown. pg 1191
Finding3	Family and health care professional's influence in the decision-making process (U)
Illustration	It was the health workers and the doctor, they said she would have to go into a home. pg 1191
Finding4	Significance of the admission route (U)
Illustration	He was brought here from the hospital. He was never home again. It was a terrible shock, a terrible shock. I could never take him home again. pg 1191
Finding5	Negative thoughts and feelings (U)
Illustration	You feel so guilty that you were so inadequate as a daughter or as a child of a parent that has to be put into a residential care. The guilt is so terrible, and it doesn't get any easier, as time goes on you still feel guilty, but you try your best to make things as tolerable as possible. pg 1192
Finding6	Positive feelings (C)
Illustration	I'm quite happy with him being there, because he's well looked after. pg 1192
Finding7	Mixed feelings (C)
Illustration	I didn't like the idea. I didn't like putting her out of the house but she had to go. pg 1192

Findings for: Strang, V. R., P. M. Koop, et al. – Clinical Nursing Research (2006); Family caregivers and transition to long-term care⁴²

Finding1	The Waiting begins - Crisis as initiator (U)
Illustration	There have been several kinds of crises. pg 33
Finding2	The waiting begins - Need for synchronicity (C)
Illustration	She wasn't that bad if you know what I mean ...I broke down and said no, we won't do it; pg 34
Finding3	The Waiting begins – Control (C)
Illustration	Who did I call first? I talked to so many people ... to see what they could do to help me with this [situation]. pg 34
Finding4	The Waiting begins – Reciprocity (C)

Illustration	He doesn't want to go out because of his difficulty in walking, he doesn't want to go in a wheelchair... so this also prevents me from going out...we [are] very much isolated pg 35
Finding5	After Placement - Deeply bonded relationships (U)
Illustration	And then because you're not there, you wonder what's happening... so you worry. pg 36
Finding6	After placement - Sorting out the change (U)
Illustration	I just have to adjust to the fact, okay, it's okay you go and have lunch, or you go to a concert, or you do this or that. Sometimes, I haven't kind of come to grips with that yet of how much time I should have to myself. pg 39
Finding7	After placement - Attempting continuity (C)
Illustration	I make her special meals, take them to the home, and leave them in the fridge. pg 37

Findings for: Sussman, T. and S. Dupuis. - Canadian Journal on Aging (2012); Supporting a relative's move into long-term care: Starting point shapes family members' experiences⁴⁶

Finding1	Acceptance Process Shaped by Starting Point (C)
Illustration	Heartbreaking, devastating, and, the worst thing [they] ever had to do. pg 399
Finding2	Pre Move Process from Home: Acceptance through Reflection and Escalating Needs (U)
Illustration	Just basically - with her falls, not eating properly (she was diabetic so she wasn't taking her insulin and she was legally blind so we weren't even sure if she was reading the numbers right when she was testing her sugar)- and we finally said look, we can't do this any more, running over there all of the time. I think it's [time] we have a look at other alternatives (daughter,01) pg 400
Finding3	Pre Move Process from Retirement Residence: Mounting Complaints with little time for reflection thwarts acceptance (C)
Illustration	We'd be getting complaints of 'she's' late for dinner or she's late for this or she's ...things like that, and that stuff was becoming an irritant at times because all of a sudden we're trying to tell her, Mom, you should do this or Mom, you should do that and you know - what are we doing to a poor lady? pg 401
Finding4	Pre-Move Process from Hospital: Acceptance forced not reached (U)
Illustration	Really, the hospital says, "We'll tell you what, you have to make an application, but you sign it and we pretend that that's your choice." I would have been happier if the hospital just said, "Because we can't keep you in an acute care bed we're gonna transfer you here," then [there would be none of this sort of pretence that this] let's pretend that the family has a choice, let's pretend that the patient has a choice" - there really is no choice. (daughter,09) pg 402
Finding5	The Moving Process: Facility factors paramount in balancing administrative demands and emotional care (U)
Illustration	You find all that out the day that you go there and Mom was wondering where I was - "Well, Mom I had to go upstairs and do this"; So if I knew all that I could fill it all out if I had that package ahead of time and I could spend more time with her because, your first day is so - critical, right - and so emotional. (daughter,04) pg 402
Finding6	Post Move Adjustment: Facility factors and resident reactions make a difference (U)
Illustration	Something good is happening to [her husband] because he's not as confused; (spouse 2) pg 403

Finding7	The Impact of Pre-Move Processes and Starting Points on Post-Move Adjustment (C)
Illustration	I expected a period of adjustment where she would get used to her surroundings...but I think she'll be OK, it'll take time to adjust. (son 06) pg 404

Findings for: Tilse, C. - American Journal of Alzheimer's Disease (1998); Continuing or refusing to care: The meaning of placing a spouse in long term care⁴⁹

Finding1	Decision-making and marital discontinuity (C)
Illustration	You deceive her to put her in there and I feel now this great feeling of guilt which I have great difficulty overcoming. pg 31
Finding2	The nature of relocation (U)
Illustration	He didn't quite understand what it was all about so we just had to take him in. So we took him in and that's where we left him. So I went off but it nearly broke my heart when he stood there and I had to leave without him. pg 31
Finding3	The Precursors of the Placement (C)
Illustration	I couldn't take it any more. pg 32
Finding4	Experiences of visiting (C)
Illustration	She's still here but she's not the same person. pg 32

Findings for: Tilse, C. - Australasian Journal on Ageing (1994); Long term marriage and long term care: We thought we'd be together till we died⁵⁰

Finding1	The Impact of Placement (C)
Illustration	When he went in I think, like, the world just dropped down on me altogether. pg 172
Finding2	The Impact of Placement - A history of living together (U)
Illustration	I wouldn't go to bed... I couldn't sleep you see. No mum. pg 172
Finding3	The Impact of Placement - An identity as part of a couple (U)
Illustration	It's like losing an arm or a leg pg 173
Finding4	The Impact of Placement - An obligation to care for each other (U)
Illustration	So I went off and it nearly broke my heart when he stood there and I had to go off without him pg 173
Finding5	Relations with the Facility (C)
Illustration	While he's there I want to be there with him as much as I can. pg 173
Finding6	Attachment and loyalty (U)
Illustration	There's a bond there. It doesn't matter how bad things get, that bond will stick