“The experience of older people permanently relocating from their home in the community to a long term care facility: A systematic review.”

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ABSTRACT

Objective: To systematically review the qualitative research relating to the experiences of older adults permanently relocating from their home to a long term care facility (LTCF).

Methods: A systematic review of qualitative research using the methodology developed by the Joanna Briggs Institute. Inclusion criteria for studies included publication in peer reviewed journals, English language papers and permanent relocation to a long term care facility within one year of the study.

Results: Following the search and appraisal phase of the systematic review a total of 14 studies (presented in a total of 15 peer reviewed journal articles) were identified for inclusion in the review. The studies covered a period of 25 years and were from 6 different countries. Study methodologies include grounded theory(5), phenomenological studies(5), case study(1), life history(1), content analysis(1) and descriptive study(1). From the studies a total of 62 findings were extracted which were categorized into 11 groups based on common themes. From the 11 categories 5 synthesized findings were identified. These related to the decision making process for relocation, aspects of deep loss and dislocation experienced by many people, the importance of maintaining control and autonomy in relation to life in the facility, the challenges of making a new life with a new sense of purpose and the complex, unique and ongoing nature of the responses to relocation.

Conclusion: The systematic review indicates that there is a significant gap in the support services for older people relocating to a LTCF. While the clinical and personal care aspects of the services in LTCFs appear satisfactory there is a failure to recognise the significant psychological and emotional issues faced by older people as they relocate and struggle to adapt to new environments, develop new relationships, learn a new set of rules to survive, create a sense of place, establish new identities and create new meaning for their lives. The review indicates there is little in the way of support for these life transition processes and many people fail to make a successful transition.
EXECUTIVE SUMMARY

Background

Long term care facilities play a significant part in the lives of hundreds of thousands of older adults, particularly in OECD countries. For over sixty years there has been concern reflected in the research literature over the adverse impact on older adults of moving into a LTCF in terms of increased mortality and increased physical and psychosocial morbidities. However, to date, there have been no conclusive results and many conflicting findings arising from quantitative research. In the 1980s a new line of research based on qualitative studies emerged and this thesis is based on a systematic review of the findings from those qualitative studies.

Objectives

To determine the best available evidence that articulates the experiences of and meaning for older people arising from their permanent move from their home to a LTCF and, from this evidence, develop recommendations to inform aged care policy makers and practitioners in meeting the needs of older people as they make the move to a LTCF.

Inclusion criteria

Types of Participants

Older people who have moved from home to a LTCF within the year prior to the study. The institution must be one that provides some level of personal or clinical care service and not just board and lodgings.

Phenomena of interest

The experience for older people associated with a permanent move into a LTCF.

Types of studies

A wide range of qualitative studies where included in the search criteria. These included, but were not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research reporting on the experiences of older people in relation to a permanent move to a LTCF. Papers in languages other than English were excluded.
Types of outcomes

Findings from a meta-aggregation of themes and categories arising from the data generated by older people and reported in the relevant qualitative studies

Search strategy

The search strategy was designed to find published research studies in peer reviewed journals. Key words were developed covering the population, phenomena, context and research type. Additionally, key words used in the literature associated with what is termed 'relocation syndrome' were used. Data bases used included Academic OneFile, Academic Search Premier, CINAHL CSA Sociological Abstracts, PsycINFO, Pubmed/Medline, Scopus, Social Services Abstracts, Sociological Abstracts (Sociofile) and Web of Science. In addition, the references of relevant articles discovered through the systematic search process were manually reviewed.

Methods of the Review

Methodological quality

Eligible publications were assessed by two independent reviewers for methodological quality using the standardised critical appraisal tools of the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).

Data Extraction

Data extraction from identified studies was conducted using the standardised data extraction tools of the JBI-QARI. Extracted information consisted of study findings and, where available, supporting evidence from research participants.

Data Synthesis

Study findings were assessed according to the JBI-QARI credibility scale and then placed in categories of similar meaning. The categories were combined, again based on similarity in meaning, into synthesised findings.

Results of the Review

The review identified 14 studies (15 articles) and generated 5 synthesized findings relating to the experience of older adults moving into a long-term care facility.
These synthesized findings were derived from 11 categories which had been developed from 62 individual findings identified from the studies. The 5 synthesized findings were:

1. A person's prior consideration of their future social and care needs, the locality of the facility and the person's participation in the move decision will have a significant influence on whether the move is accepted or resisted;

2. A person moving into a LTCF may experience a sense of homelessness and feelings of deep loss in many aspects of their life;

3. The ability to make valued decisions within the LTCF and to maintain links to people, places and objects from pre-facility life contributes to a sense of self and autonomy, the nature of which is under continuous threat from pressures to conform and fit to the norms and routine of the LTCF;

4. A person's process of acceptance or resistance to a LTCF relocation and their feelings and reactions to the move are complex and will differ dramatically both in the nature of the responses and the timing of those responses; and

5. The challenges of learning how to live in a LTCF and of making a new life are significant and difficult requiring substantial effort on the part of the older person.

**Conclusions**

Notwithstanding the review studies covered a period of 25 years and 6 different countries there was a remarkable consistency in the experiences reported by the various research participants. This systematic review of the evidence from qualitative research provides a poignant picture of the struggles and challenges facing many older adults as they enter a LTCF. Each person entering an aged care facility faces their own unique struggle as they move from the known world of their home to an alien world of the aged care facility, trying to retain a sense of their own personhood and create a sense of place meaningful to them as they are pressured to conform to the will of the institution. The uniqueness of the struggle is reflected in the emotional responses which vary considerably in nature, intensity and timing. The entry into a LTCF is not a one-time event but a continuing process that for some is never resolved.
The staffing of LTCFs is typically based around the management of the clinical and bodily frailties of older adults and so the professional staff are usually clinically trained registered nurses supported by ancillary nursing staff and personal carers. The review reveals no material negative experiences in relation to the content of the care (i.e. clinical and basic support) albeit there are issues about the routine nature of the service delivery. Given the emotional and psychological challenges facing many older adults as part of their relocation, the review raises concerns of the adequacy of the existing staffing models and/or professional training provided to staff to enable an adequate and appropriate response to address the profound psychosocial needs of newly admitted older adults and whether sufficient resources are given to address this aspect of people's lives. One of the hopes of this review is to raise the awareness of policymakers, administrators and the nursing profession of the significant gaps that exist in this area.

Based on the accounts in the review studies many admissions to LTCFs would be classified as involuntary. A typical pattern of an involuntary admission is a slow decline in frailty experienced by the person followed by an adverse incident such as a fall leading to hospitalisation and subsequent admission to a LTCF. The admission process is often driven by concerned children and/or family doctor and while usually done with the best intentions leads to significant difficulties in achieving a successful transition to a LTCF. The second major hope of this review is to raise the awareness of policymakers and administrators to resource a more sensitive and supportive transition process and to raise the awareness of family doctors and relatives to balance their legitimate concern for the older people's physical well-being with that of their psychological well-being.

Older adults moving into LTCFs are amongst the most vulnerable people in our community. Despite a research history going back more than 60 years that has continually raised a concern about the transition into LTCFs and the potential negative impact on a person's emotional and psychological well-being, and ultimately their physical health, there is no material indication that policymakers, aged care administrators or the nursing profession have developed and implemented a considered response to this issue. The third hope is that the impact of institutionalisation will get the same attention as was provided to people with disabilities and their struggle with institutionalisation in the latter part of the 20th century.
Implications and Recommendations for Policy Makers

The provision of aged care services in economically developed countries is subject to significant government involvement in terms of policy, regulation and funding. It is important therefore that governments are provided with the best available evidence concerning the provision of aged care services and any identified gaps. This systematic review has identified a number of gaps in the provision of aged care services based on the psychological and emotional needs of older people moving into the LTCFs.

It is recommended that policy makers review the following recommendations with a view to minimising harm that may result from a move to a LTCF:

To reduce the harm resulting from involuntary admissions:

- Initiating an awareness program for family doctors, hospitals and LTCFs on the potential harm from involuntary admissions and providing information as to what would constitute a sensitive and supportive decision-making processes for families; and

- Investigating the need for service funding to support and facilitate appropriate decision-making processes for older people recently admitted to hospital and at risk of LTCF institutionalisation.

To reduce the harm arising from the sense of homelessness, alienation and depersonalization when moving to a LTCF:

- Identifying and implementing strategies to impact on the decision making processes and transition process to a LTCF so as to minimise the harm arising from the sense of homelessness, alienation, and depersonalization;

- Identifying strategies that LTCFs can implement to reduce the sense of homelessness and alienation and actively promote those strategies to LTCF administrators and professional staff;

- Providing funding for area based social workers to assist LTCFs identify and address the psychological and emotional needs of older adults as they move into the facility; and

- Identifying the unique professional knowledge and skills required by nursing
staff within LTCFs and providing funding to tertiary institutions to incorporate that knowledge into professional nursing education.

Implications and Recommendations for Practice

LTCF administrators and the nursing profession have a significant influence on the allocation of staffing resources, staffing mix and service delivery models within facilities. Given the desire to ensure the best possible outcomes for older people not only clinically but for their emotional and psychological wellbeing and quality of life experience it is important that both administrators and nursing professionals make the decisions on the best available evidence. This systematic review has identified practice and/or service delivery gaps which if addressed may help to reduce the harm arising out of the institutionalisation of older adults.

It is recommended that administrators and nursing professionals review the following recommendations with a view to making appropriate changes to service delivery within LTCFs.

To reduce the harm resulting from involuntary admissions:

- At the time of an enquiry or application for admission ensure the older person and/or family are provided with information as to the best possible decision making processes and the possible consequences of involuntary admissions.

To reduce the harm arising from the sense of homelessness and alienation when moving to a LTCF:

- Provide education for all staff in relation to the sense of homelessness and alienation experienced by many older people moving into a LTCF; and

- Identify strategies that can be used in relation to each individual person to support them in establishing a sense of place and connection within the LTCF as quickly as possible in a way that is meaningful to them.

To reduce the harm arising from the sense of depersonalization when moving to an LTCF:

- Review the decision making process for all aspects of the LTCFs activities that have a bearing on the life of each older person and develop ways of significantly increasing, in a meaningful way, the involvement and participation of older
people in both the decision making and the activities themselves; and

- Ensure sufficient resources are provided to enable people who live in a LTCF to have the opportunity and support to participate in occupations/activities based on activities that are meaningful to them.

**Implications and Recommendations for Research**

The review identified a number of areas that would benefit from further research:

- The nature and effectiveness of pre-planned responses to relocating to a LTCF;

- The awareness and understanding of the staff of LTCFs about the difficult nature of the relocation to a LTCF by older people;

- To what extent, if any, there is a sense of impotence or inadequacy felt by staff regarding their ability to adequately respond to the needs of residents experiencing difficulties with a relocation to a LTCF;

- The nature of the relationship between residents and staff and to what extent this contribute to a resident's sense of wellbeing within the LTCF;

- The awareness by family members and family doctors as to the range of outcomes experienced by older adults moving into a LTCF and the extent to which an awareness of the negative risks may impact on the decision making process;

- The role of the family doctor in relation to involuntary admissions and how the role may be enhanced to reduce the harm resulting from involuntary admissions;

- The development, trialling and evaluation of alternative transition support programs in relation to the decision-making and move associated with relocating to a LTCF;

- Identification of the necessary knowledge and skills required to support the psychosocial and emotional aspects of an older person's life in their transition to and within a LTCF and an evaluation of the capability and capacity of existing LTCF staffing models to provide those requirements;

- An evaluation of the adequacy of the current divisional therapy and/or lifestyle programs within LTCFs in relation to meeting the individual older persons need
for meaningful occupation; and

- Phenomenological research into the experience of a permanent relocation to a LTCF focussing on the extent to which this leads to a 'world collapse or breakdown' for those making the relocation, the way people are impacted and the way in which they respond.

The value of meta-aggregation in synthesizing the available evidence from the qualitative research in a particular field is evident from this systematic review, however one of the limitations of the review is the undeveloped literature around meta-aggregation methodology as part of the evidence-based practice movement. This is an area that would also benefit from further research.

**Keywords**

systematic review; long term care facility; nursing home; relocation; relocation stress; older adults; meta-aggregation; qualitative research; synthesis; evidence based practice
STATEMENT OF PERSONAL INTEREST

For over 20 years I was a senior administrator responsible for the running of long term care facilities. I came from a finance and administrative background and initially managed the LTCF operations from that perspective which appeared to fit with the clinical focus of the service.

Over the years I gradually gained a sense that something was not quite right. We passed all the Government required standards and undertook innovative work in relation to aged care building design. But the longer I worked the more uneasy I felt. Why where so many people entering into the facilities and not thriving? Indeed, many people did not survive long following admission to a LTCF. Their deaths appeared more to be related to their will to live rather than their frailty or chronic conditions. Many people who have worked in aged care for a length of time are familiar with the phenomena of the “light going out” of peoples' eyes not long before they decline and die. This for me has become a significant question: Why do the lights go out?

Since that time, the teams I have worked with have developed some innovative programmes and been fortunate enough to win several national awards. The programmes were based on a concept of well-being and focused on the psychosocial aspects of living in aged care. The work was based on the knowledge of motivated practitioners and their experiences. We could find very little in the literature to shed light on the phenomena or that provided much in the way of guidance, mainly due to the lack of time, research skills and the difficulty associated with identifying what appeared to be a sparse and ill-defined body of literature.

This thesis is a direct result of wanting to know what the research literature is reporting about the experiences of people moving to aged care. While it does not provide an answer to my main question it is designed to respond to the premise; if we understand better the experiences of older people moving into a long term residential aged care facility is it possible to improve our service responses to, at the very least, reduce the negative aspects for people making this arduous transition? Having completed the work I am now surer than ever that the answer is yes.

By way of personal philosophical position I view my world as comprising both natural and social phenomena. Intellectually my natural ontological philosophy
would best be described as a form of scientific realism while my social ontology would be characterised as constructed idealism. Not surprisingly my epistemological position is one of constructivism. None of these positions is "pure" and most of the time I experience and enjoy life as a "naïve realist" disregarding the constructed nature of my world.

**Stephen Richards**

29\textsuperscript{th} November 2011
DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other territory institutions to Stephen John Richards and, to the best of my knowledge and belief, contains no material previously published a written by another person except where due reference has been made in the text.

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Stephen Richards
29th November 2011
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First of all I would like to thank my wonderful wife who has encouraged me to undertake these studies and has been both patient and supportive in the amount of time away from income production that this has meant.

To the Joanna Briggs Institute and Professor Pearson I owe sincere thanks for accepting me as a student even though my career path has been managerial in focus, both academically and occupationally, and with no significant research background. I am also grateful for the support and guidance Professor Pearson has provided as my supervisor. There is also a profound sense of gratitude as the project I embarked upon proved to be somewhat of a life buoy during a very difficult period of 'my lived experience'.

Christina Hagger has been terrific as friend, mentor and co-supervisor. The time spent talking with Christina and having to articulate what at times was a confused muddled of thoughts was most valuable.

To the many people I have known living the last years of their life in an aged care institution I owe my greatest debt. You have helped me to appreciate the value and dignity of life in a way that has enriched me beyond measure.

Stephen Richards
29th November 2011
CHAPTER 1. INTRODUCTION

This chapter provides an introduction to the thesis by placing the research in context, outlining the anticipated outcomes and providing a detailed background to the previous research interest in the relocation phenomenon.

The Context of the Study

The overall purpose of the study was to determine, through an analysis of qualitative research, the best available evidence that articulates the experiences of older people arising from their permanent move from their home to residential long term care.

The study therefore includes the experiences of permanent relocations by older people from their home to a residential aged care facility. Relocations where the prior permanent living setting was an institution were excluded. No exclusions were made on the basis of culture or geographic setting.

The Anticipated Outcomes of the Study

The outcomes of the systematic review were designed to be in the form of synthesized findings from a meta-aggregation of primary qualitative research findings pertaining to the experience of older people moving into institutional long term care. It was hoped that this meta-aggregation, through the rigours of the systematic review process, would provide a richer picture and thus improve understandings of the relocation phenomena.

A better understanding of the relocation phenomena may inform care practices in meeting the needs of older people in what will, in most cases, be the last major move of their life and may inform aged care policy in determining the nature of the additional services required in relation to the psychological and emotional needs of older people arising out of the relocation.

Background to the Review

The world is ageing at an increasing and unprecedented rate never before experienced by humanity. Globally the fastest growing segment are people aged over 60 and within this group the fastest growing are the very old, those aged over 80\(^1,2\). The situation is similar in Australia with the number of people aged 65 - 85
years expected to double by 2050 and the number of people older than 85 expected to quadruple to over 1.8 million\textsuperscript{3}. The impact of the ageing of the Australian population has been recognised in recent years\textsuperscript{3,4} and one of the responses has been a significant increase in residential aged care services (up 30\% to 175,472 residential places between 1995 and 2008) and community aged care services (up from a low base, by 1907\% to 48,483 home care places over the same period)\textsuperscript{5}.

Residential aged care is a significant part of the lives of many Australians. In 2008 53,737 people entered permanent residential aged care and another 51,293 entered for temporary respite care. For permanent admissions as of 2008 the average length of stay was 3.03 years for women and 2.11 years for men\textsuperscript{5}.

Given the significance of ageing in our society it is not surprising there is a long history of research interest on the impact of moving (relocating) into an institutional long term care facility. The early research in this area extends back for approximately 65 years with one of the first studies, by Camargo and Preston, appearing in 1945\textsuperscript{6}. A recent limited literature search revealed 9 English language journal publications for the first five months of 2010\textsuperscript{7-13} showing that interest in this area still remains strong six and a half decades on.

In a review of the literature reported in 1969 Lieberman\textsuperscript{14} articulates one powerful reason for this ongoing interest when he comments that the research was one of "humanitarian concern"(p330) in relation to the impact on the "psychological well-being and physical integrity"(p330) of older people arising from institutionalization. The research concern originally arose out the results of the early studies which suggested that mortality rates post transfer to a care facility were higher than expected for older people\textsuperscript{6,15-19}. Camargo and Preston\textsuperscript{6} reported mortality rates 2½ to 11½ times the rate found in the general population for people aged over 65 during the year following admission to 'mental hospitals' while Aldrich and Mendkof\textsuperscript{17} reported that the "social and psychologic effect" from relocation can be "lethal"(p192). The concern is also reflected in the differing terminology used in relation to the effects of relocation. For example the terms relocation stress, relocation syndrome, relocation trauma, translocation syndrome, translocation trauma, and transplantation shock have all been used throughout the history of the literature\textsuperscript{20-22}.

Although the earlier studies found increased mortality rates from relocation these
were followed by some studies that report no mortality effect or even a positive effect from relocation\textsuperscript{23-26}. As a consequence drawing conclusions from these apparently conflicting research findings was difficult. This was attributed to the differing measures used\textsuperscript{23} and compounded by a number of methodological problems in the studies such as small population sizes, the lack of comparability in populations, and differing research approaches\textsuperscript{27-29}.

In parallel with mortality research there emerged a growing focus on broader morbidity effects arising from the relocation of older people. Many of these morbidity studies reported a variety of negative consequences associated with relocation, including depression, increased sense of loneliness and alienation, decrease in functional competence, cognitive decline, decline in general condition and even more extreme morbidity and mortality outcomes, such as falls, injuries, behavioural problems or premature death\textsuperscript{30-37}. As with the mortality studies, the reported negative morbidity effects of relocation are inconsistent with studies reporting positive outcomes such as improved emotional well-being, enhanced environmental awareness, increased activity participation and greater social engagement\textsuperscript{35, 38-41}. A number of the mortality and morbidity studies reported that the significant portion of the negative impacts observed occurred in the initial period following relocation, usually in the first three months. This observed phenomenon was named the three month effect\textsuperscript{17, 23, 42}.

These equivocal results on both the morbidity and mortality effects of relocation still continue and after more than half a century of research there remains no research consensus as to the effect of relocation on the well-being of older adults\textsuperscript{35, 43-45}. This perhaps reflects the difficulties of researching the area. One difficulty, noted in the early 1960's\textsuperscript{17}, is determining whether the reported increase in morbidity or mortality rates is associated with the move \textit{per se}, due to health factors or due to separation from family because it was generally declining health that precipitated a relocation to an institution. Several years later Blenkner\textsuperscript{23} reflects this difficulty noting that many of the early studies reporting increased mortality rates are based on admissions of elderly people to 'mental hospitals' and involved many people with possibly critical pre-existing health conditions.

Questions have also been raised about study design. In the 1970s Lieberman\textsuperscript{27} challenged the research community over the disparity of research approaches,
methodological problems and a "lack of elegance" in random design and quasi-experimental methods. Similar sentiments have been echoed in later decades\textsuperscript{20, 25, 46}. The issue of study design and mortality/morbidity rates were subject to a public and at times acrimonious debate in the early 1980s that was played out in the prominent journal, The Gerontologist. Borup and colleagues published two articles\textsuperscript{47, 48} reporting on the relocation of 529 patients from one nursing home to another in which they concluded that there was no adverse mortality effect from the relocation. Based on a review of the research they went on to conclude more generally that there was no support for a negative mortality effect from relocation. What followed was a series of published articles\textsuperscript{49-51} in which the Borup studies were alternatively criticised and defended\textsuperscript{50, 52, 53}. This debate was primarily around study design and review methodology and exemplified two aspects of the research, firstly the difficulty of research design in the field and secondly the passion associated with the "humanitarian concern" that underlies this issue. That mortality based research continues with findings in relation to mortality effects that are both adverse\textsuperscript{33} and not adverse\textsuperscript{54} reflects the ongoing inconclusive nature of this research area.

One premise of the early work on the relocation effect was around what has been characterized as a "pure relocation effect"\textsuperscript{20}. This suggests that it is the move itself, independent of factors preceding or following the move that lead to adverse effects. In his 1981 review Coffman\textsuperscript{20} found positive, neutral and negative effects of relocation consistent with a normal distribution of effects and so concluded that it is not the relocation itself that causes the adverse effects. Coffman suggests that where adverse effects occur it was the factors surrounding the move that give rise to the relocation outcome\textsuperscript{20, 53} rather than the move itself. He does suggest that a pure relocation effect probably does exist but that it is a pure stress effect arising out of the relocation. He reports, however, that he could not find evidence for this in the studies reviewed because stress was not isolated as a factor.

Following from Coffman's assertion, that there are particular factors associated with relocation that are responsible for the adverse effects, researchers have tried to identify those factors. Studies report that the following factors influence the outcome from relocation; involuntary rather than voluntary relocation\textsuperscript{55-57}, the degree of difference between the environment of the original location to the final destination\textsuperscript{54, 58-61}, the degree of participation and choice by the person making the move\textsuperscript{29, 56, 62}, and the amount of support and preparation involved in the move
process\textsuperscript{56, 60, 63, 64}. In addition to these factors there is recognition by a number of researchers that there are different types of relocations that must be considered; home to institution, institution to institution and within the institution\textsuperscript{29, 35, 65}. More recently there is emerging research for relocations involving moves from retirement villages to LTCFs\textsuperscript{66} suggesting this should be treated as a separate type of relocation. While this work on relocation factors has so far failed to produce conclusive results it continues to be regarded as a fruitful line of enquiry with researchers recommending further work in the area\textsuperscript{66-68}.

Until the 1980's the focus of research was on quantitative based studies. Emerging in the literature in the 1980's is a line of enquiry based on qualitative approaches, with one of the first being a grounded theory study by Chenitz\textsuperscript{69}. While slow to pick up momentum, there were sufficient qualitative studies for Lee, Woo and MacKenzie to publish the results of a non-exhaustive literature review and synthesis on older people's experiences of nursing home placement in 2002\textsuperscript{70}. As part of the relocation experience the researchers identified themes of feelings of loss and suffering, sense of relief and security, passive acceptance, making the best of available choices, and reframing. A second integrated literature review of the qualitative literature by Brandburg\textsuperscript{71} included 13 studies following their search phase. However this study was designed to develop a transition model to a LTCF and did not summarise themes in relation to the experiences of older people.

Qualitative studies since the Lee, Woo and McKenzie literature review have reported similar and consistent themes. Couglan and Ward\textsuperscript{72} reported themes of waiting, grieving the loss of personhood, and the importance of relationships with family, staff and other residents. Tsai and Tsai\textsuperscript{73} report themes of a temporary home, highly structured lifestyle, restricted activities, safety concerns and relationships while Heliker and Scholler-Jaquish\textsuperscript{74} report themes of becoming homeless, getting settled and learning the ropes and creating place. The last three themes are not presented as an easy process and the authors commented "Residents have left not only a home but a part of who they are. They are grieving their loss, each in their own way and in their own time."\textsuperscript{74}(p41)

No systematic review of the experiences of older people in relation to their move to residential aged care have been found following a search of Academic OneFile Academic Search Premier CINAHL CSA Sociological Abstracts, PsycINFO,
PubMed/Medline, Scopus Social Services Abstracts, Sociological abstracts (Sociofile) or Web of Science.

Given the lack of conclusive research from quantitative studies and the absence of a comprehensive systematic review of the qualitative literature in relation to the relocation experience of older people it is argued that such a systematic review of qualitative studies will add to the understanding of this phenomena. Further, consistent with both the quantitative and qualitative research findings to date it is argued that the systematic review should be limited to permanent relocations from home to residential aged care institutions and be limited to studies reflecting the experiences of people who have lived in the residential aged care facility for less than one year. One year was chosen as emphasis is on the relocation experience and not the experiences of older people well after the relocation.
ABBREVIATIONS AND DEFINITIONS

Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ALF</td>
<td>Assisted Living Facility</td>
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<tr>
<td>EBP</td>
<td>Evidence Based Practice</td>
</tr>
<tr>
<td>JBI</td>
<td>Joanna Briggs Institute</td>
</tr>
<tr>
<td>JBI-SUMARI</td>
<td>System for the Unified Management, Assessment and Review of Information</td>
</tr>
<tr>
<td>JBI-CReMS</td>
<td>Comprehensive Review Management System</td>
</tr>
<tr>
<td>JBI-QARI</td>
<td>Qualitative Assessment and Review Instrument</td>
</tr>
<tr>
<td>LTCF</td>
<td>Long term care facility; a residential long term care institution providing some level of personal or clinical care service and not just board and lodgings.</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation of Economic Cooperation and Development</td>
</tr>
<tr>
<td>QES</td>
<td>Qualitative Evidence Synthesis</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized control trials</td>
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</table>

Definitions

Meta-analysis | The synthesis of findings from quantitative research. |
Meta-synthesis | The synthesis of findings from qualitative research to produce findings more substantive than the individual studies. |
Meta-aggregation | The synthesis of findings from qualitative research to produce declamatory or directive statements to guide practitioners and policy makers. |

Definition of “older person”.

There is no consistent age marker for "old age" in the literature. For example, in economically developed countries Denton and Spencer\(^75\) report that the age marker of 65 has been regarded as the commencement of “old age”, the World Health Organisation\(^76\) suggests that the “chronological age of 60 or 65” has been used in developed countries while Foot and Fisher\(^77\) note that the medical literature commonly uses age 70. The use of a specific age is regarded as arbitrary because unlike puberty there is no commonly experienced specific physiologically event to signify the onset of “old age”\(^77\), rather ageing is a continuing process experienced differently by different people\(^78\). Formal age markers for ‘old age’ have often arisen
due to the need to define a recognised retirement age\textsuperscript{78} or qualifying age for the receipt of a pension. In developing countries, however, the circumstances of many people are significantly different with often much lower life expectancy rates\textsuperscript{79}. In view of this, while also recognising that the setting of any number for the determination of “old” is arbitrary, the World Health Organisation\textsuperscript{76} agreed that an age of 50 for “old” better reflects the situation of older persons in developing countries.

The differing circumstance of people not only exists between countries but also within countries. By way of example, the life expectancy for Australians as a whole is currently reported as 82\textsuperscript{79} but when looked at in closer detail the reported life expectancy of Aboriginal and Torres Strait Islander males is 11.5 years shorter than non-indigenous males\textsuperscript{80} and the reported life expectancy of indigenous females is 9.7 years shorter than their non-indigenous counterparts. These intra-country differences are not generally reflected in the literature.

In view of the above, while recognising the arbitrary nature of an age marker, the review protocol included studies of people from economically developed countries of 60 years and over and of people from developing countries or indigenous populations of 50 years and over. However no studies from developing countries or indigenous populations were identified in the search process.
CHAPTER 2. THE SYSTEMATIC REVIEW METHODOLOGY

This chapter provides an introduction to the science of evidence synthesis, placing the JBI meta-aggregation methodology within the broader context of research synthesis, explaining the methodological basis of the research and providing an overview of the methods used.

OVERVIEW OF THE SCIENCE OF EVIDENCE SYNTHESIS

The purpose of the review is to determine the best available evidence that articulates the experiences of older people arising from their permanent move from their home to residential long term care with the aim of informing aged care policy and practice and thus this review falls within the ambit of evidence-based practice, the core of which "is the systematic review of the literature on a particular issue"\(^{81}\) (p 48).

Traditionally the main focus in evidence based health care has been the systematic review of quantitative research which has its origins in the late 1970's with the work of Archie Cochrane and the eventual establishment of the Cochrane Collaboration in the early 1990s\(^{82}\). Within that genre the systematic review of randomized control trials (RCT) has been regarded as the gold standard for decision making for many years\(^{83, 84}\) and today very few researchers would question the value of such reviews in establishing the evidence for guidance and practice\(^{85}\).

Today systematic reviews of both quantitative and qualitative research are regarded as the highest level of evidence because they systematically search, identify, and summarize the available evidence around a particular clinical question or phenomena with a particular emphasis on the quality of the study methodology or credibility of opinion or text\(^{86}\).

It is now recognised that the provision of health care "involves complex, multifactorial decisions that require a range of evidence"\(^{87}\) (p68) and that many research questions cannot be addressed by "trying to fit them within the tight jacket of experimental design\(^{82}\) (p748). Popay and Williams have identified a number of areas in healthcare for which qualitative synthesis could provide evidence including the exploration of taken for granted practices, understanding both lay and clinical behaviour around interventions, identifying patients’ perceptions of quality and the
evaluation of complex policy initiatives\textsuperscript{88}. It was from this recognition of the potential role that qualitative synthesis could fulfil in health care that attention was given to the development of the systematic reviews of qualitative studies by researchers such as Pearson\textsuperscript{86}.

The application of qualitative research synthesis for health care is just one aspect in the broader history of qualitative synthesis. The first published qualitative synthesis is generally credited to sociologists Glaser and Strauss\textsuperscript{89, 90} in 1971 while the work that is credited with establishing the popularity of qualitative synthesis is Noblit and Hare's book\textsuperscript{91} on the meta-ethnography method published in 1988\textsuperscript{85, 90, 92, 93}. While there are now a number of methodologies developed including meta-ethnography, meta-study, thematic synthesis, narrative synthesis, content analysis, formal grounded theory, cross-study analysis and meta-aggregation\textsuperscript{84} it is meta-ethnography that appears to be the preferred synthesis method\textsuperscript{94-96} for researches undertaking a meta-synthesis. Stern and Harris\textsuperscript{97} are credited\textsuperscript{92, 98} with christening this family of methodologies as ‘meta-synthesis’ in 1985.

Within healthcare the increasing use of qualitative synthesis has been gradual. In 2001 Evans and Pearson\textsuperscript{93} commented that there was a "growing discussion in the healthcare literature addressing the synthesis of qualitative research" and that there had been "a small number of views published"(p 112). In 2007 Dixon-Woods, Booth & Sutton reported that the number of publications reporting syntheses of qualitative research is now "rapidly increasing" however their review of qualitative synthesis studies in nursing and healthcare between 1994-June 2006 only included 42 papers. It is not surprising then that for the systematic reviews of qualitative research findings it has been noted that there is still just a small but slowly growing literature\textsuperscript{81, 99, 100}.

Apart from the small numbers, there have been concerns raised over the quality of meta-synthesis studies. In 2001 Evans and Pearson report\textsuperscript{93} that of reviews published there was often limited or inadequate information provided in the research reports of the processes and methods used for searching, inclusion and quality criteria which inhibit the ability to appraise the trustworthiness of the review itself. In 2007 Dixon-Woods and colleagues\textsuperscript{101} report on a methodological review of 27 meta-synthesis papers in which they identified a number of quality issues:

\begin{itemize}
  \item Methods for searching not identified;
\end{itemize}
• Key words used in searching not identified;

• Failure to use methodological terms in addition to subject-specific terms in the search (e.g. the term ‘qualitative’); and

• Reporting of the use of techniques such as meta-ethnography and yet the reported findings were not recognizable as a meta-ethnography.

Another methodological review of meta-synthesis reports released in 2007 by Bondas and Hall reports on a review of 45 studies and identifies a number of common problems with the quality of the reports including:

• Incomplete analysis, a lack of synthesis or the opposite, an over-theorization of the findings;

• Interpretations that were not data based or where the categories or themes developed could not be traced back to the data;

• Confusion in the use of concepts and their applications, for example ‘themes’, ‘categories’, ‘thematic categorises’, ‘metaphors’; and

• Failure to apply claimed methodologies in full for example studies applying the Noblit and Hare meta-ethnography yet failing to describe a refutational relationship or the comparability and differences in the findings.

Any meta-synthesis designed to meet the needs of evidence based healthcare has to address quality issues such as these. While the above are recent studies the need to address the quality of the primary studies included in systematic reviews was recognised earlier as an important aspect of developing an appropriate systematic review methodology. In 2004 Pearson reported on the results of a project to develop an initial approach to synthesize the evidence from non-quantitative research that addresses these issues by using the concepts previously developed for quantitative systematic reviews utilised in evidence based practice by the Cochrane Collaboration. This 2004 project was, in effect, a response to Pearson's and others concerns about the absence of qualitative evidence within the evidence based movement.
The 2004 project developed a methodology, since named meta-aggregation, through a consensus group project initiated by the Joanna Briggs Institute in 2001. The consensus group consisted of senior academics from various Australian Universities and several staff members from the Joanna Briggs Institute. The group developed a systematic process for extracting, appraising and synthesizing data from qualitative research studies in a manner that would reflect the rigours that are applied to the meta-analysis of RCTs within a systematic review framework. The aggregative approach that was developed reflected the nature of the interpretive and critical perspective understandings of phenomena, addressed many of the issues concerning transparency in the processes of synthesis, and ensured that the synthesized findings were linked back to the data and that the results of the review would be usable by policy makers and practitioners. A detailed description of the project is reported by Pearson\textsuperscript{81} and Hannes & Lockwood\textsuperscript{84}.

The JBI meta-aggregative approach is specifically designed to translate qualitative research findings into 'lines of action' that are generally directive in nature\textsuperscript{84}. There is now a library established by JBI where examples of the meta-aggregative approach can be found (http://connect.jbiconnectplus.org/JBIReviewsLibrary.aspx). The meta-aggregation model by the Joanna Briggs Institute is also documented in detail in the JBI Reviewers Manual\textsuperscript{102}. The manual has been used as the basis for the systematic review reported in this thesis.

An outline of the main differences between meta-synthesis and meta-aggregation and why the latter is the methodological approach taken in this thesis is contained in the following section.
DISCUSSION OF THE METHODOLOGICAL BASIS OF THE RESEARCH

When initially researching the impact of relocation to a long term care facility I focused on quantitative research. This quantitative research has a long history extending from contemporary research back to the early 1950's but despite this extensive period of research there is still no consensus relating to the impact of relocation. An alternative line of enquiry based on qualitative approaches emerged in the 1980's and while slow to pick up momentum there have been sufficient qualitative studies for a non-exhaustive literature review. However, to date, there has been no systematic review of this qualitative research published. A review of this literature is provided in the background section in Chapter 1. The unresolved nature of the quantitative research, the emergence of a small body of qualitative research and the absence of any systematic review of the qualitative research led to my decision to address the gap in the literature by undertaking this systematic review using JBI's methodology.

As mentioned in the preceding section, in addition to JBI's meta-aggregation there are a number of other qualitative synthesis methodologies so the question “Why is the meta-aggregation methodology the most appropriate for this thesis?” must be addressed. While these methodologies have a number of common methods including formulation of objectives, inclusion criteria, and extraction of findings there are a number of differences including an alignment to different epistemological frameworks and differences in methods associated with the scope of searching, critical appraisal of studies, and approach to synthesis. JBI's meta-aggregation uses methods which are specifically designed to address the needs of policy makers and practitioners in health care. Another key difference between JBI's meta-aggregation and other meta-synthesis methodologies is the underlying goal of the research which ultimately informs the methods used. There is general agreement as to the goal of most meta-synthesis methodologies described by Finfgeld as the production of "new and integrative interpretation of findings that is more substantive than those resulting from individual investigations". These methodologies may provide suggestions for concrete actions but these are drawn from the completed synthesis exercise rather than being the outcome of the synthesis exercise itself. Meta-aggregation seeks to move beyond new interpretive findings and produce, as part of the actual synthesis process, declamatory or
directive statements to guide practitioners and policy makers. In summary the goals of meta-synthesis and meta-aggregation are different and this is reflected in the differing methods and accordingly meta-aggregation has been selected because it is considered the most appropriate for the purposes of this thesis.

The philosophical underpinning for JBI's meta-aggregation is the philosophy of pragmatism which has informed the approach in order to "meet the challenges of delivering readily usable findings, based on the voices of relevant stakeholders displayed through qualitative research reports." Meta-aggregation also maintains a "sensitivity to the contextual nature of qualitative research" and to an interpretive and critical understandings of the phenomena under investigation. Mirroring the rigour of the Cochrane Collaborations approach to systematic reviews, the meta-aggregation methodology emphasises a comprehensive and systematic approach to searching for relevant studies and stresses the importance of methodological quality of studies to be included.

As the goal of JBI's meta-aggregation is to produce 'lines of action' for practitioners and policy makers from the best available evidence the focus is on identifying and bringing that evidence in a readily usable form. This can be seen in the JBI three phase approach to meta-aggregation; identifying the study findings (phase 1), categorizing the findings based on similarities of meaning (phase 2) and finally developing synthesized findings from the categories to develop the 'lines of action' (phase 3). Although the decision on developing categories and synthesized findings is the reviewers these must be made based on the study findings and reviewers should read and re-read the studies to become familiar with all the findings before commencing the categorizing and final synthesis.

The logic of inquiry for the methodology is contained within the JBI format for systematic reviews of qualitative studies and specifically within the methods operationalized within a software program called JBI-SUMARI (System for the Unified Management, Assessment and Review of Information). This software, which has been internationally peer reviewed was developed to assist researchers in the systematic review processes. In the research for this thesis there were two JBI-SUMAI software modules used to manage the systematic review process, the Qualitative Assessment and Review Instrument (JBI-QARI) software and the Comprehensive Review Management System (JBI-CReMS) software. JBI-CReMS is designed to guide a researcher through the systematic review process including
the initial research protocol, study selection and extracting descriptive data from the studies. JBI-QARI is designed to manage, appraise, extract and synthesize qualitative data as part of a systematic review of evidence. The JBI software was used to manage the systematic review incorporated in this thesis.

In summary the systematic review of qualitative studies undertaken as part of this thesis is pragmatically driven in that its objective is to provide guidance to practitioners and policy makers based on the best available evidence in relation to the experiences of older people relocating to LTCFs. While retaining sensitivity to interpretive and critical understandings of phenomena under investigation the methodology mirrors the rigorous approach to synthesizing qualitative data used by the Cochrane Collaboration's approach to the synthesis of quantitative data. Underpinning the methodology is an emphasis on the transparency of methods, the quality of included studies and the credibility of findings.
METHODS

This section outlines the methodology undertaken for the systematic review of evidence in relation to this thesis. The methodology used was the JBI methodology for conducting systematic reviews of qualitative research studies as described in the Joanna Briggs Institute Reviewers Manual 2008 edition\textsuperscript{102}. As described in the preceding section, in undertaking the review two software based instruments developed by JBI were used, JBI-CReMS and JBI-QARI.

The methodology described by JBI has prescribed roles for the primary and secondary reviewer throughout the systematic review exercise. As this review is undertaken towards a Master in Clinical Science degree the two reviewers were used only for the critical appraisal and study inclusion steps and I (the primary reviewer) was solely responsible for all other aspects of the review. The second reviewer, Dr Christina Hagger, is also the associate supervisor for my thesis.

Criteria for Considering Studies for Inclusion

Types of studies

The review considered qualitative studies that reported on the experiences of older people who have recently (within a year prior to the study) made a permanent move (relocation) into a LTCF from their home.

Where a study included the experiences of older people who have made the move together with the experiences of others (e.g. family or staff) associated with the move these studies were also included however only the experiences of the older person were extracted.

The review identified and included studies that focused on qualitative data resulting from differing research methodologies. The research methodologies from included studies were grounded theory, phenomenology, life histories studies, case study, content analysis and a descriptive study.

Papers in languages other than English were excluded.

Types of participants

The review considered the experiences of older people admitted on a permanent basis to a residential long term care institution which provides some level of
personal and/or clinical care service and not just board and lodgings.

The review did not differentiate between studies involving subsets of older people (e.g. subsets based on specific morbidities such as dementia, ethnicity, gender or other specific differentiating characteristics). The data synthesis and analysis did not indicate materially differing results associated with subsets of older people. In some cases people with dementia were excluded by the researcher from participating in the primary research study. Several studies were from Hong Kong and aspects unique to these studies are reported in the study findings.

The review was limited to participants who have lived in the residential aged care facility for one year or less as the phenomenon of interest is the experiences associated with the move into the facility.

Notwithstanding the definition of "older person" used (refer definitions section) there were no studies that identified participants as being indigenous Australians and there were no studies from other than economically developed countries.

**Phenomena of interest**

Studies were included only if they reported on the phenomena of interest of the review, which is the meaning and experience for older people of a permanent move into a LTCF.

**Review Methods**

**Search Strategy**

The search strategy was designed to find research studies published in peer review journals. A three-step search process was utilised.

As a first step a limited and unstructured search of MEDLINE, CINAHL and Google Scholar was undertaken to identify sample literature in the area of the review. The initial key words used to commence this search are listed in Appendix II -Table 1.

The second step was an analysis of the title, abstract and keywords from the articles identified in step one in order to establish a comprehensive keyword search table (Appendix I Table 2). The keywords from Table 2 formed the basis of the comprehensive search. Titles and abstracts from studies located in the
comprehensive search were reviewed to identify potentially relevant articles. The full paper for potential articles were retrieved and reviewed. The third search step was a review of the reference list of all relevant articles from step two to identify any other further relevant studies. All full papers retrieved were assessed against the study inclusion criteria.

The databases searched were those containing peer reviewed published articles. The databases used are listed in Appendix I-Table 3. In conducting the search using the key words in Appendix I-Table 2 alternative spellings and possible meaningful prefixes or suffixes of key words were used. For CINAHL, MEDLINE and Scopus databases relevant thesaurus terms were also used in the search process as part of step two. The thesaurus terms were identified from the terms assigned by the particular database to the articles returned from the searches using the pre-prepared keywords.

In addition to the keywords a search filter was used to identify qualitative studies. The words used in this filter are included in Appendix II-Table 2.

Allowance was made in the event that there were insufficient research studies from the above steps to expand the search to include grey literature sources (Appendix I, Table 4) however this step was not required.

The search included only English language studies.

Assessment of quality

Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standard critical appraisal instruments from JBI-QARI (Appendix II).

Before commencing the appraisal stage the reviewers agreed on a common understanding of the criteria in the appraisal tool and the standards for inclusion or exclusion for this particular review.

Appraisal Criteria Rules

The approach JBI takes to appraisal of quality is contained within the JBI-QARI appraisal tool and guidelines for the application of the tool are contained in the JBI Reviewers' Manual. The appraisal of the quality of qualitative papers is based on appropriateness and transparency and covers the following:
• The research methodology selected should be appropriate for the purpose for which the research is being undertaken. The purpose is often interlinked with a particular research paradigm.

• The research questions and objectives should be consistent with the purpose of the research.

• The research methodology selected should be appropriate to address the research questions/purpose.

• The methods used for collecting, analysing, interpreting data are consistent with the methodology and the reported conclusions are consistent with these processes.

• The participants are adequately represented via appropriate direct and relevant quotations and/or descriptions.

• There is appropriate disclosure of the researcher’s biases' and influence on the research.

• Research is ethical for the time the research was undertaken.

From this approach JBI has developed 10 specific criteria which are to be applied to qualitative papers. Due to the diverse nature of qualitative research approaches these criteria cannot be applied in a rigid or dogmatic manner and the appraiser must make decisions as to how each criterion is to be applied based on the nature and purpose of the papers. The primary and secondary reviewer discussed and agreed the following criteria upon which to include or exclude studies based on the results of applying the JBI-QARI appraisal tool. As part of the discussion the reviewers also agreed their understanding of the criteria as described in the JBI Manual.

The results of the discussion on the criteria are below:

Criteria 1: There is congruity between the stated philosophical perspective and the research methodology.

There are a range of 'philosophical perspectives' and for simplicity JBI has reduced the range of perspectives to three broad headings (positivist, interpretive, critical). Authors may also use other terminology to describe a philosophical or theoretical approach, e.g. post-positivism, feminism, and constructivism. Where a reviewer is
unclear as to the nature of the named theoretical position they should discuss it together, and seek advice if needed before agreeing how to interpret and apply the named perspective.

In some instance research papers may not specifically name the research paradigm or philosophical standpoint used. In these cases the reviewer is to 'intuit' the perspective used based on the stated objective and content of the paper.

Criteria 2: There is congruity between the research methodology and the research question or objectives.

No further clarity was considered necessary.

Criteria 3: There is congruity between the research methodology and the methods used to collect data.

No further clarity was considered necessary.

Criteria 4: There is congruity between the research methodology and the representation and analysis of data.

No further clarity was considered necessary.

Criteria 5: There is congruity between the research methodology and the interpretation of results.

No further clarity was considered necessary.

Criteria 6: There is a statement locating the researcher culturally or theoretically.

For this systematic review a specific description of the cultural situation is not considered critical but is regarded as important. There may not be a direct statement to this effect in the paper itself but this may be implied from the information contained within the paper. In this review the range of papers appraised covers different cultures (e.g. English speaking participants living in Australian to Chinese speaking participants living in Hong Kong) and it was clear from the studies which broad-based culture the researcher is located. This is considered important as relocating to a LTCF may have particular cultural meaning.

Criteria 7: The influence of the researcher on the research, and vice-versa, is addressed.
No further clarity was considered necessary.

**Criteria 8:** *Participants, and their voices, are adequately represented.*

For this systematic review this criteria is considered critical. Through descriptions of participants histories, experiences, descriptions of their stated feelings, impressions, etc. and verbatim quotes of participants the paper should present a sense that the research is grounded in the phenomena being investigated and is portraying the participants view of the phenomena.

**Criteria 9:** *The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body.*

No further clarity was considered necessary.

**Criteria 10:** *Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data*

No further clarity was considered necessary.

**Exclusion/Inclusion based on criteria**

Each criterion was appraised as to whether or not the criteria was met or was unclear based on the information contained within the study. (e.g. Y = met; N= not met; U = unclear). Following separate appraisals the two reviewers met and discussed any differences in appraisal criteria assessments. There were no differences following this step.

Prior to the appraisal of the studies the two reviewers reached a consensus for determining the inclusion of studies based on the assessed criteria. The consensus was based on the nature of the study, the evolving nature of qualitative research and the need for an acceptable level of study quality. For the purpose of this systematic review inclusion/exclusion based on appraised quality is based on the following:

**Criteria 1, 2, 3, 4, 5, 8:** Any criteria not met (N) excludes paper. More than two unclear (U) appraisals excludes the paper. (These criteria considered critical to study quality.)

**Criteria 6, 7, 9, 10:** Three not met (N) criteria leads to exclusion (These criteria are considered important to study quality but individually are not regarded as critical unless the study indicates otherwise.)
Data Extraction

Descriptive data was extracted from the papers included in the review using the standardised data extraction tool from JBI-QARI (Appendix III). The data extracted included specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review objectives.

Data Synthesis

Following data extraction the included studies were re-read and the study findings from each study were identified and entered these into JBI-QARI. For the purposes of JBI-QARI a finding is a conclusion reached by the researcher and may be presented as a metaphor, theme or concept, i.e. the emphasis is on the researcher's findings not the reviewer's re-interpretation of findings. Together with each finding extracted, textural data that supports or illustrates the finding was identified and recorded in JBI-QARI. This data maybe in the form of a direct quote from a participant, an observation or a statement. The level of congruity between the findings and the supporting textural data was then graded into one of three levels of credibility as required by the JBI-QARI analytic module. These are unequivocal, credible and unsupported and are shown in the statement of findings represented by the letters U, C and Un respectively. The description of these levels of the evidence is as follows:

Unequivocal – relates to evidence beyond reasonable doubt which may include findings that are a matter of fact directly reported/observed and not open to challenge.

Credible – relates to those findings that are, albeit interpretations, plausible in light of the data in a theoretical framework. They can be logically inferred from the data. Because the findings are interpreted they can be challenged.

Unsupported – is when the findings are not supported by the data.

After recording all the findings in JBI-QARI the study findings were read several times and then categorised by similarity of themes. The categories were then read a number of times and allocated to a synthesized finding based on the similarity in
meaning. The synthesized findings were used as the basis to determine recommendations.

This chapter has presented the methodology for undertaking this systematic review of qualitative studies. The findings, categories and synthesized findings are presented in the results chapter with the recommendations presented in the final chapter. Each finding is presented with supporting illustrations extracted from the studies.
CHAPTER 3. RESULTS

This chapter reports on the results of the systematic search, the results of appraisal, a description of the studies and the results of the data synthesis.

RESULTS OF SYSTEMATIC SEARCH

Before the search was undertaken a University of Adelaide research librarian, Ms Maureen Bell, was consulted on ways to implement the search. The advice received in relation to setting up a search table (refer Appendix I) in order to break down the search into manageable units proved particularly helpful. There were 7,920 articles identified during the systematic search which came down to 3,237 potential articles after the removal of duplicates. Following a review of titles and abstracts the number of potential articles was reduced to 108 for which the full text was retrieved. All articles were reviewed to determine a match against the inclusion criteria and during the process the article references were scanned for further articles that may fit the inclusion criteria. The additional scanning resulted in a further 10 articles being retrieved and from the total of 118 articles 16 were identified as meeting the inclusion criteria.

All 16 studies were reviewed by the primary and secondary reviewer and following critical appraisal 1 article was excluded on methodological grounds. Of the remaining articles it was identified that 2 were reports on the same study and a decision was made to treat the 2 articles as a single report for the purposes of extracting the findings. Diagram 1 displays the search process.
Diagram 1 Search Results
RESULTS OF APPRAISAL

Based on the JBI-QARI appraisal tool only one study was excluded as it did not meet criteria 8 (Participants, and their voices, are adequately represented). Of the remaining 15 studies:

- 1 met 9 of the 10 criteria
- 14 met 8 of the 10 criteria

Criteria 6 (There is a statement locating the researcher culturally or theoretically) was not met by 14 of the studies. Criteria 7 (The influence of the researcher on the research, and vice-versa, is addressed) was not met by any of the studies. The underlying philosophical position informing the study methodology was not implicitly stated in most studies. Guidance was sought from Professor Pearson as to how to assess this aspect of the appraisal. Following discussion with Professor Pearson we were able to establish all the studies to be within the interpretive philosophical position by reference to the methodology and reviewing the article in its entirety for any inconsistencies with that position, i.e. for any indication of incongruity between the methodology and the philosophical position that informs that methodology.

Overall the standard of quality of the articles was assessed as being of a quality suitable for inclusion in the systematic review.

There were no unresolved differences arising between the two reviewers in relation to the appraisal criteria and assessment as to the inclusion or exclusion of a paper.

A list of included and excluded studies is contained in Appendix IV.
DESCRIPTION OF THE STUDIES

A total of 15 papers were included in this review reporting on 14 studies (refer Table 5 below). Appendix IV provides information on methods, phenomena of interest and conclusions from the studies extracted using the JBI-QARI extraction tool.

All the studies were from the interpretive theoretical perspective with differing methodologies. The number of studies from each methodology is as follows:

- grounded theory studies 5
- phenomenological studies 5
- life history studies 1
- case studies 1
- descriptive studies 1
- content analysis 1

The studies are from 6 different countries:

- USA 7
- Canada 2
- China (Hong Kong) 2
- UK 1
- Australia 1
- New Zealand 1

In terms of sample sizes 4 studies had less than 10 participants, 6 studies between 10 and 20 participants, 1 study had between 20 and 30 participants and the remaining three had between 30 and 42 participants. Two articles from Hong Kong are reports from the same study but at different time frames. To ensure there was no duplication of findings the two articles were treated as a single study and duplicate findings were not included.

The included studies covered a period of 25 years with the majority of studies occurring in the latter half of this period as indicated by the following;
• 1983 to 1984  1
• 1985 to 1989  1
• 1990 to 1994  0
• 1995 to 1999  4
• 2000 to 2004  3
• 2005 to 2008  5

Table 5: Description of studies

<table>
<thead>
<tr>
<th>Date</th>
<th>Author</th>
<th>Country</th>
<th>Theoretical perspective &amp; Study Type</th>
<th>Participants No</th>
<th>Participants Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1983</td>
<td>Chenitz</td>
<td>USA-Calf-San Francisco</td>
<td>Interpretivism Grounded theory</td>
<td>22F; 8M</td>
<td>63-96; mean 79</td>
</tr>
<tr>
<td>1989</td>
<td>Brooke</td>
<td>USA - Washington (West Coast)</td>
<td>Interpretivism Grounded Theory (not stated)</td>
<td>31F; 11M</td>
<td>65-98; mean 84.5</td>
</tr>
<tr>
<td>1996</td>
<td>Iwasiw etal</td>
<td>Canada - Ontario</td>
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<td>Hong Kong - Chinese</td>
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<td>USA - Texas</td>
<td>Interpretivism Hermeneutical - phenomenological</td>
<td>10</td>
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<tr>
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<td>Marshall &amp; Mackenzie</td>
<td>Australia - NSW - Newcastle</td>
<td>Interpretivism Phenomenology</td>
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<td>Over 65</td>
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<td>2008</td>
<td>Barredo &amp; Dudley</td>
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RESULTS OF META-AGGREGATION OF QUALITATIVE RESEARCH FINDINGS

Meta-aggregation of the study findings included in the review generated 5 synthesised findings. These synthesised findings were derived from 11 Categories which in turn were an aggregation of 62 study findings.

The results are presented first in a graphic form based on the JBI-QARI presentation format showing the relationship between study findings, category and synthesized finding. The reference number on the study finding is the study number plus the finding number in that study, i.e. 14.2 represents study 14 and the second finding extracted. The tabular form shows each category for a synthesized finding, the findings that comprise that particular finding and illustrations supporting each finding. The study reference for each finding is given together with the page number reference for each illustration. The assigned levels of credibility (U=unequivocal, C=credible, Un= Unsupported) is recoded at the end of each finding. At the end of each synthesis finding section is a narrative summary for the synthesis and a table summing up the evidence credibility ratings by category.
**Synthesised Finding 1:**

A person's prior consideration of their future social and care needs, the locality of the facility and the person's participation in the move decision will have a significant influence on whether the move is accepted or resisted.

<table>
<thead>
<tr>
<th>Synthesised Finding</th>
<th>Category</th>
<th>Study Findings</th>
</tr>
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<tbody>
<tr>
<td>1.1 Voluntary moves were characterised by a deliberation over time, consultation with family and an easier transition to LTCF life while involuntary moves involved little active involvement by the person and resistance to LTCF life.</td>
<td>Category 1</td>
<td>1.2 Older adults experienced losses in physical function prior to admission and a perceived loss of control regarding the decision towards LTCF placement. (U)</td>
</tr>
<tr>
<td>Synthesis 1</td>
<td></td>
<td>6.1 For residents who participated in the decision making to enter the LTCF there was a range of Influences including physical, social, medical, financial and familial. (S)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.2 The decision making about admission which was characterised by two separate experiences being those who were involved in the decision and expressed a readiness to be admitted and those who did not participate in the decision and resisted the admission. (S)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14.1 For (voluntary) moves into an assisted living facility the angst surrounding the decision is an important concern with the trigger and validating rationale for the final decision to move being a deciding event, usually a falls, immediately before the decision Nonetheless there may be prior deliberations for a move. (S)</td>
</tr>
<tr>
<td></td>
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<td>15.1 Moving to the facility was either self-motivated (e.g. ongoing concerns over declining health or the desire to be near family) or in response to familial concerns (e.g. to appease family concerns over health) or involuntarily (e.g. placed by family). (S)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13.1 Participants who had lived in an area for a considerable time chose to move into a home they “knew” or were familiar with thus making implicit or explicit links between their choice and their personal histories, helping to maintain a sense of self in the familiar. (S)</td>
</tr>
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<td></td>
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<td>13.2 Some participants chose homes because of their closeness to amenities or public transport routes and in doing so took account of their current life style and social networks. (U)</td>
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<tr>
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<td></td>
<td>13.4 Participants often defined belonging in terms of their place of birth in a locality defined by historical boundaries even though those boundaries were often obliterated by new developments and places not shown on maps thus the place of belonging became a form of “secret geography” shared only by those with this intimate knowledge. Locality also defined public transport access and moving out of locality made visits by friends dependant on local transport difficult, thus breaking the ties to these long relationships. (U)</td>
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Diagram 2 Synthesised Findings 1
**Category 1.1** Voluntary moves were characterised by a deliberation over time, consultation with family and an easier transition to LTCF life while involuntary moves involved little active involvement by the person and resistance to LTCF life.

**Findings in this category:**

1.2 Older adults experienced losses in physical function prior to admission and a perceived loss of control regarding the decision towards LTC placement\(^{105}\). (U)

*Illustrations of loss of physical function*

- Andrew: “Uh, what put me here - I fell and hurt myself.” [p89]
- Connie: “… I had several light strokes... I fell in the bathroom … I'm almost blind.” [p89]

*Illustrations of perceived loss of control.*

- Andrew: “I realize that, uh, she would really go off her rocker without me. Our kids put us here...under our, uh, not-be-knowings...they just got tired of fooling with us... I give my daughter a power-of-attorney, and that's where I made my mistake.” [p89]
- Dottie: “I had one member of the family (daughter) that wanted me to be at the nursing home. [p89]”

6.1 For residents who participated in the decision making to enter the LTCF there was a range of influences including physical, social, medical, financial and familial\(^{106}\). (U)

- A former businessman said "I decided that I couldn't look after a 5 bedroom house any longer and it was an actual burden as well ... I did my own cooking, got my own meals, looked after myself. Then you get to the point where you can't do that anymore." [P47]
- Another man with a close relationship with his daughter stated "I talked to my daughter and she agreed. She thought it was ok to come here.” The daughter concurred "He wanted to go [to the LTCF] because of being lonely in wintertime. He wanted to be around old people . He pretty well decided that's what he wanted to do." [P47]

7.2 The decision making about admission which was characterised by two separate experiences being those who were involved in the decision and expressed a readiness to be admitted and those who did not participate in the decision and resisted the admission\(^{107}\). (U)

*Involved in decision making*

- "This place was my first choice right from the heart ... this is what I wanted. I wanted to come here because I didn't want to my children to be
burdened by my problems.” [p384]

Not involved with decision

- "My husband made the decision. The doctor called me and he said that he wanted to put me into a nursing home. I didn't know anything.” [p384]

- "I didn't want to leave home. They never gave me a chance ... I was railroaded.” [p384]

14.1 For (voluntary) moves into an assisted living facility the angst surrounding the decision is an important concern with the trigger and validating rationale for the final decision to move being a deciding event, usually a fall, immediately before the decision notwithstanding there may be prior deliberations for a move^{108}. (U)

- Fran, a 91 -year-old resident who had lived by herself in the home where she had raised her children, stated: "I've lived alone for years, so I'm used to being alone. I would prefer to go home, but that would make my daughter have more worries and I don't want that. I fell in my kitchen and dislocated my shoulder.” [P371]

15.1 Moving to the facility was either self-motivated (e.g. ongoing concerns over declining health or the desire to be near family) or in response to familial concerns (e.g. to appease family concerns over health) or involuntarily (e.g. placed by family)^{109}. (U)

- A few of the residents claimed their deteriorating health and inability to keep up with household demands prompted their move. “We talked about moving before I broke my hip. I couldn't do the work “ snow and grass,” said one participant. [P29]

- Another commented: “My daughter brought me here because I needed supervision. I had fallen at home, and I laid there for two days.” [P29]

Category 1.2 The choice of LTCF can impact on a person's sense of belonging and opportunities to continue friendships and maintain participation in activities.

Findings in this category:

13.1 Participants who had lived in an area for a considerable time chose to move into a home they “knew” or were familiar with thus making implicit or explicit links between their choice and their personal histories, helping to maintain a sense of self in the familiar^{110}. (U)

- One participant was adamant about her choice when offered alternatives: "I thought about going in to 'Lonsdale' [residential home], I never thought about anywhere else. I don't know anything about those others, I just know that one.” [P863]
13.2 Some participants chose homes because of their closeness to amenities or public transport routes and in doing so took account of their current lifestyle and social networks\textsuperscript{110}. (U)

- Some people did not expect neighbours and friends to make a special trip to see them and so chose facilities based on people being able to “drop in” hence maintain the social connections. As one participant explained why she chose a facility near a town centre: “People will call in on their way to the shops. They’ll just call in, like, they won’t have to go out of their way. They might pop in to see if there’s anything I want that they can get for me while they’re at the shops”[P864].

13.4 Participants often defined belonging in terms of their place of birth in a locality defined by historical boundaries even though those boundaries were often obliterated by new developments and were not shown on maps, thus the place of belonging became a form of “secret geography” shared only by those with this intimate knowledge. Locality also defined public transport access and moving out of locality made visits by friends dependant on local transport difficult, often breaking the ties to these long relationships\textsuperscript{110}. (U)

- On participant responded if he “came from” the village in which he was living at the time of the interview: “Oh no, I don’t belong here. I didn’t move here until I was eight’. He had lived in the “new ” village for over sixty years and despite a store of memories and relationships he did not feel like he belonged to it. [P865]

- Interviewing a participant in her home a researcher asked if she “came from” the village in which she was living. The reply was quite adamant, “No, I’ve never lived there, I’ve always lived here. You wouldn’t catch me living there, I’ve always been a [village X] woman’. The researcher could see the other village from the participant’s home but had failed to notice the signpost demarking the boundaries between villages. [P865]

- One participant, who had wanted to move into a home in her village, was persuaded by her family to move into one a few miles away but this meant that visits by friends in her old village were impossible on public transport and despite staff encouraging the family to bring friends it did not happen and so the staff arranged lifts with their minibus which enabled the participant to maintain links with her friends in her old village which otherwise would have been impossible, and friendships lost. [P866]

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**Synthesised Finding 1:**

*A person’s prior consideration of their future social and care needs, the locality of the facility and the person’s participation in the move decision will have a significant influence on whether the move is accepted or resisted.*
The decline in the ability of older people to attend to the basics of daily living is a common precursor to relocation to a LTCF for both voluntary and involuntary relocation\(^{105-109}\). Voluntary moves were characterised by a period of consideration before the move\(^{106-108}\) including the impact the decline in abilities would have on family members\(^{106, 108, 109}\) and then the final decision to move is often triggered by an event such as a fall\(^{108}\). For involuntary moves there is no evidence of any prior acknowledgement of a need to relocate by the older person in the studies and the decision is often made by the elder's family\(^{72, 109, 111}\).

People who made the decision to move to a particular LTCF did so for a number of reasons including their prior knowledge of the facility, proximity to amenities, accessibility by existing friendship networks while moving away from existing areas may result in a breakdown in established friendship networks\(^{110}\).

### Summary of Evidence Credibility – Synthesised Finding 1

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<tr>
<th>CATEGORY</th>
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<th>CREDIBLE</th>
<th>UNSUPPORTED</th>
<th>TOTAL</th>
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Table 6: Summary of evidence credibility - synthesis finding 1
Synthesised Finding 2

A person moving into LTCFs may experience a sense of homelessness and feelings of deep loss in many aspects of their life.

<table>
<thead>
<tr>
<th>Synthesized Finding</th>
<th>Category</th>
<th>Study Findings</th>
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</thead>
<tbody>
<tr>
<td>1.1 People from the same population group identify common cohort associated losses arising out of lived experience. (U)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.3 As a consequence of their placement in LTC people experience a loss of control, loss relating to family relationships and loss of activity level. (U)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.1 There is a significant contrast between home and the nursing home marked by a loss of purpose, lack of activity and loss of role with the family relationships. (U)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.3 The experience of moving out and moving in involved all aspects of shifting from home to the facility and the various decisions about divesting of property and possessions, what to keep and what to take to the facility and those who had decided to move to the LTCF found these decisions easiest. (C)</td>
<td></td>
<td></td>
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<tr>
<td>11.2 Participants described leaving the home as being one of the most difficult aspects of moving into a hostel and identified the value and importance of bringing personal possessions with them to make the hostel “feel a bit homely”. (U)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.3 Throughout the first 6-month period, residents shared stories of home and most residents yearned to return to their homes, to what was, and talked about losing their purpose in life, feeling that they’re doing nothing constructive while in the ALF. This life review through the sharing of their stories, remembering their lives, who they are, and what continues to be meaningful to them can be viewed as part of the grieving process, as both sad and supportive. (U)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.3 The circumstances under which a person enters a nursing home can be such that a person is unlikely ever to feel at home again, anywhere. (C)</td>
<td></td>
<td></td>
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<tr>
<td>3.1 The first phase of adjustment was disorganisation which was characterised by feelings of displacement, vulnerability and abandonment. (U)</td>
<td></td>
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<tr>
<td>5.1 Becoming homeless was a constitutive pattern that emerged primarily during the first month after admission and related to the understanding of leaving one’s home, the experience of becoming homeless, and entering an unfamiliar place. (U)</td>
<td></td>
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Diagram 3 Synthesised Findings 2
Category 2.1 On admission into a LTCF people may feel a sense of loss across many aspects of their lives including loss of control, loss of role meaning, loss of relationships, loss of activity and loss of possessions which may continue a life course of individual and cohort loss.

Findings in this category:

1.1 People from the same population group identify common cohort associated losses arising out of lived experience. (U)

- Individuals belonging to this cohort share common life experiences, including being born around World War I, growing up during the great depression, and fighting in World War II and even the Korean War. Individuals in this cohort are aware of the potential for personal losses, and of the need at times to sacrifice. Their identification with such losses and the consequent grief is typical, especially for people of advanced age.[p90]

- Edward: “I had a hard life, but it was good. Me and 4 brothers lived during the depression… We had to make do with what we got… Coached for 49 years.” [p89]

- Beatrice: “...My father died when I was 3 years old...My husband died. I had 1 daughter...she died.” [p89]

- Andrew: “they're all [the children] we got [now], just the two. We had 5 altogether.” [p89]

1.3 As a consequence of their placement in LTC people experience a loss of control, loss relating to family relationships and loss of activity level. (U)

Illustrations in relation to the loss of independence

- Respondents unanimously expressed dissatisfaction with their loss of independence. They responded variously concerning the inability to come and go at will, the inability to determine their own eating and grooming schedules, and the lack of privacy that is an unavoidable consequence of communal living in such close quarters, as is typical in LTC. [p89]

- Andrew: “Well, I couldn't explain it. I know is uh, just laying here looking at these 4 walls is not very pleasant. Whenever you know you could take care of yourself, and be outside when it's pretty weather. If I had my way about it, I'd be out here mowing the yard or something else … I'm able to do it.” [p90]

Loss of family relationships

- [p91] Andrew expressed the concept of “disowning” children over perceived acts of betrayal connected to entrance into LTC, and Dottie made many comments about the betrayal from one daughter and the loss of her old connectedness to another daughter, noting the many regular activities that ended with her entrance into LTC.
**Loss of activity levels**

- Edward “I just don't do anything, and I was into everything. I was on the city council for a time - about 6 or 7 years. at my age I'm not gonna go anywhere anyway. I'm not gonna advance in anything.” [p90]

2.1 There is a significant contrast between home and the nursing home marked by a loss of purpose, lack of activity and loss of role with the family relationships\(^{112}\). (U)

- George: "At home you can walk outside, I had a big vegetable garden. I could always find plenty to do, to keep your hands busy, mind busy, see something for it. We seldom bought a vegetable all my married life. But, ah, at home the kids are out, there is always kids, the grand-kids or now great-grand-kids." [p8]

- George: "[now I] Go for walks, that's all .... They are long days. And if you don't sleep they are long nights too." [p8]

7.3 The experience of moving out and moving in involved all aspects of shifting from home to the facility and the various decisions about divesting of property and possessions, what to keep and what take to the facility and those who had decided to move to the LTCF found these decisions easiest\(^{107}\). (C)

- For people who had decided to move to the LTCF there was little overt sadness associated in giving up their homes or possessions or concern about how their belongings would be distributed as they no longer seemed personally invested in their material goods. [p384]

11.2 Participants described leaving their home as being one of the most difficult aspects of moving into a hostel and identified the value and importance of bringing personal possessions with them to make the hostel 'feel a bit homely'\(^{113}\). (U)

- In relation to having to leave their home one resident described it as "like having your right arm cut off" while another said "it nearly broke my heart to leave my home." [P128]

- "I wanted to make it [hostel] as much like home as I could you know, that's why I've got so much around me." [P128]

- "You've got to take things that are dear to you that you can look at and reflect on ... You can look at them and say 'that's me; that's me, not someone else." [P129]

14.3 Throughout the first 6-month period, residents shared stories of home and most residents yearned to return to their homes, to what was, and talked about losing their purpose in life, feeling that they're doing nothing constructive while in the ALF. This life review through the sharing of their stories, remembering their lives, who they are, and what continues to be meaningful to them can be viewed as part of the grieving process, as both sad and supportive\(^{108}\). (U)

- In the words of Janice: "I still have my home and want to go back home."
But a lot of other people feel that I need the assistance ... they're afraid I'm going to fall again. I thought it [assisted living] would be more like home. Well, I'm trying to keep a good attitude towards here." [P372]

**Category 2.2** Many people experienced a sense of homelessness on the initial move into a LTCF was characterised by a sense of displacement, vulnerability and abandonment which for some is never resolved.

**Findings in this category:**

2.3 The circumstances under which a person enters a nursing home can be such that a person is unlikely ever to feel at home again, anywhere. (C)

- George: "At hospital they said ... to me one day 'oh, tomorrow I am taking you for a car drive.... We are going to take you around to look at some beautiful homes around here.' And I thought they were talking about 'homes' you know.... They put me in a wheelchair then into a car the next day.... Well I was here ...[voice trails off].... I was angry, I yelled, I thought I had been kidnapped. I didn't know where I was. I didn't have a penny, no matter on me, not a cent. I had no keys to the front door of my house or home. I had nothing! Talk about a lost kid, by gosh!" [p6]

- George spent the first six weeks in a secure dementia unit before being reassessed and moved to another part of the facility. There was no evidence in his admission details, medical records, care plan or progress notes to indicate why he needed a specialist dementia unit. Even five months later the memories from that time were especially painful: George " ... one night I had to get up six times to get somebody out of my room. One of them used to use the hand basin for a ... [voice trails off]. It was hard." George asked to have the tape recorder turned off while he described being physically assaulted by another resident during that period. [p7]

3.1 The first phase of adjustment was disorganisation which was characterised by feelings of displacement, vulnerability and abandonment. (U)

**Displacement:**

- "I don't belong here, it's a mistake." [p67]

- "It's backwards, I can't explain it to you. I'm just too old to figure this out." [p67]

**Abandonment**

- "I feel like I am stranded with no one to have confidence in." [p67]
• "They put me down here, when I’ve no reason to be here just because I have pneumonia. There is nothing wrong with me, I can’t see it any other way.” [p67]

Vulnerability

• "My parents died, my husband died, and then I came here.” [p67]

• Loss of physical or mental abilities was also traumatic. One wished to see but had poor vision, another wished to speak but was aphasic, still another longed to cook or keep house but was crippled with arthritis. the most threatening, however, was the loss of cognitive ability. Losing valued possessions - furniture, a home - also was painful. [p67]

5.1 Becoming homeless was a constitutive pattern that emerged primarily during the first month after admission and related to the understanding of leaving one’s home, the experience of becoming homeless, and entering an unfamiliar place.74 (U)

• Anna sold her large home, moved to a new apartment in another section of the facility and shortly after to the nursing home: “Four months I was there, and loved every minute of it, except I was so busy trying to get everything settled. I don't regret one minute being over there. I want to go back to my apartment; it's a whole house full of memories. The only thing I've regretted is falling and being where I am now [nursing home]. You see the whole story is that if you can't do for yourself, they have different places for you.” [p37]

• Regina, an 85-year-old woman with expressive aphasia, tried hard to describe what it was like for her to be at the facility. She cried out, “They don't know the meaning of me! They don't know the meaning of me.” [p38]

• The awareness of being in an unknown and unfamiliar neighbourhood was described by another resident as “What was is no more.” [p38]

• Another new resident, Alice, further described this: “You don't know what it's like...you lose your identity for being able to do what you want to do when you want to do it. But that's my story so far.” [p38]

Synthesised Finding 2

A person moving into LTCFs may experience a sense of homelessness and feelings of deep loss in many aspects of their life.

People entering a LTCF from the same age cohort may share common experiences of difficult times such as growing up in the depression or fighting in a major war105 and have experienced losses and sacrifices as part of these common lived
experiences. Many people have experienced significant personal loss through the
death of family members, including children\textsuperscript{105} or spouse. The move to a LTCF
continued this history of loss with losses in independence\textsuperscript{105}, losses in family
relationships\textsuperscript{111, 112}, losses in activity levels\textsuperscript{111, 112}, loss of purpose\textsuperscript{108, 111} and loss of
home and possessions\textsuperscript{64, 108}. For people who had entered a LTCF voluntary, i.e. had
given prior consideration to the relocation, the loss of home and possession may
cause little overt sadness\textsuperscript{107}. Involuntary relocations may also result in a person
never feeling at home again\textsuperscript{112} or feeling a sense of displacement, abandonment or
homelessness\textsuperscript{67, 74}.

Summary of Evidence Credibility – Synthesised Finding 2

<table>
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<tr>
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Table 7: Summary of evidence credibility - synthesis finding 2
Synthesised Finding 3

The ability to make valued decisions and to maintain links to people, places and objects from pre-facility life contributes to a sense of self and autonomy which is under continuous threat from the pressures to conform to LTCF norms and routines.

<table>
<thead>
<tr>
<th>Synthesized Finding</th>
<th>Category</th>
<th>Study Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 A basic condition affecting the elders' response was the centrality, or importance, of the admission in their struggle for independence and autonomy control over their life, or control over how and where they would live. (C)</td>
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<tr>
<td>14.2 Older people understood that they needed assistance when they first decided to move into the ALF, but they were not prepared for the increased levels of dependency on staff and by the third month, the residents told stories of losing control of decision making and independence which was viewed as a major blow to their self-esteem and identity and they talked about feelings of embarrassment, frustration, anger, and helplessness associated with this. (U)</td>
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<tr>
<td>15.2 The struggle for the desired independence versus the necessary dependency on others proved difficult, and for some independence was found in making choices around participation versus non participation in activities while the dependency on others was made difficult by not being able to depend on staff at times. (C)</td>
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<tr>
<td>7.5 In the first two weeks following admission people placed a greater emphasis on pre-existing relationships and activities although those whose admission was voluntary were proactive in commencing new relationships within the facility while those opposed to admission appeared overwhelmed by feelings of anger and depression remaining emotionally distant from others. (C)</td>
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<tr>
<td>6.3 The nature and quality of relationships was an ongoing focus for residents with family relationships continuing without any noticeable change, new peer relationships reflecting the interpersonal style of the resident and relationships with staff reflecting both a desire to maintain pre-admission roles and their vulnerability in the LTCF. (U)</td>
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<tr>
<td>14.4 During the fifth and sixth months the importance of family and friends was a recurring theme as residents began to talk more about the significance of these relationships along with the loneliness of no longer having the same level of familiar social support with those residents who did not develop relationships within the facility dwelling on this sense of loneliness and loss while for others who developed new relationships creating a new community, a new support system. (U)</td>
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<tr>
<td>6.6 The expectations that residents would fit into routines and norms of the LTCF conflicted with their innate desires to continue to be the individuals (ie maintain identity &amp; personhood) they were before admission. (C)</td>
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<tr>
<td>7.4 Adapting to the LTCF including making the facility feel like home which included residents personalising their rooms and participating in enjoyable activities. (C)</td>
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<tr>
<td>15.3 While ties to family were important so were memories of home and the past which were linked to particular possessions and these familiar memory links were important in influencing adjustment to the new living environment. (U)</td>
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</tbody>
</table>
Category 3.1: People struggled to maintain independence and autonomy and while the need for assistance was recognised, the degree of loss of independence within the LTCF was not anticipated and proved difficult resulting in a loss of self-esteem and feelings of helplessness.

Findings in this category:

4.1 A basic condition affecting the elders' response was the centrality, or importance, of the admission in their struggle for independence and autonomy control over their life, or control over how and where they would die\(^{69}\). (C)

- An elder's perception of the degree of disruption that a nursing home admission would produce in his or her control was central. [p93]

14.2 Older people understood that they needed assistance when they first decided to move into the ALF, but they were not prepared for the increased levels of dependency on staff and by the third month, the residents told stories of losing control of decision making and independence which was viewed as a major blow to their self-esteem and identity and they talked about feelings of embarrassment, frustration, anger, and helplessness associated with this\(^{108}\). (U)

- Gail is a 78-year-old woman who had previously lived alone voiced her feelings: “I've aged quite a bit. I can't do anything for myself now. I miss running my own household. To depend on one of the nurse aides is very embarrassing.” [P371]

15.2 The struggle for the desired independence versus the necessary dependency on others proved difficult, and for some independence was found in making choices around participation versus non participation in activities while the dependency on others was made difficult by not being able to depend on staff at times\(^{109}\). (C)

- Although participants appreciated services offered, they admitted at times it was difficult to depend on employees of the institution. [P30]

- Independence was found by the choices residents made to attend social activities, monthly resident meetings, individual exercise programs, church services, guest speakers from museums, and trips off grounds. These choices were selected with more regularity by some than by others. [P30]
Category 3.2 Relationships with families remained important however the loss of the previous level of interaction and support was a concern which, in some cases, was partially compensated by new peer relationships and in other cases, where there were no new relationships, resulted in people dwelling on feelings of loneliness and loss.

Findings in this category:

7.5 In the first two weeks following admission people placed a greater emphasis on pre-existing relationships. Those whose admission was voluntary were proactive in commencing new relationships within the facility while those opposed to admission appeared overwhelmed by feelings of anger and depression remaining emotionally distant from others. (C)

- One resident was taken to a specialist's appointment by a neighbour, followed by dinner at a restaurant, which was a routine they had followed before admission. [p385]

- New residents voluntarily admitted tried to be helpful, particularly to roommates. As one resident expressed "I'm trying to be friendly and helpful where it is needed. Co-operative. All those things." [P385]

- Those residents who opposed admission appeared overwhelmed by their feelings of anger, depression and shock, they seemed to remain focussed on themselves and emotionally distant from others. [P385]

6.3 The nature and quality of relationships was an ongoing focus for residents with family relationships continuing without any noticeable change, new peer relationships reflecting the interpersonal style of the resident and relationships with staff reflecting both a desire to maintain pre-admission roles and their vulnerability in the LTCF. (U)

- One resident continued outings with family for tea, another regularly played cribbage with a daughter. Another resident noted "That [brother's visit] is really important .. and my sisters if they come ... that's very important." [P48]

- One resident commented "we're all in the same field [veterans] .. we're all equal and that's what I like about it." [P50]

- At 2 weeks there were few comments about staff. At 6 weeks one said "The nurses are sweet." By 6 month resident's perception of staff became an important factor in their appraisal of the LTCF. On resident said "I'm not that foolish ... with people that are helping me. I'm not going to raise hell with them." [P50]

14.4 During the fifth and sixth months the importance of family and friends was a recurring theme as residents began to talk more about the significance of these relationships and with the loneliness of no longer having the same level of familiar social support. Those residents who did not develop relationships within the facility dwelt on a sense loneliness and
loss while others developed new relationships creating a new community, a new support system\textsuperscript{108}. (U)

- Those who did not develop relationships with other residents or staff dwelled on the loneliness of not being with their families as much anymore ("My family doesn't come to see me very often. They're too busy with their own lives"). [P372]

- Some of the women gained a new support system. "A new ALF family" as described by one woman. [P372]

**Category 3.3** Continuing to be the same person was important but conflicted with the norms and routines of the LTCF and so links to familiar people, places and objects were important to maintain this sense of identity.

**Findings in this category:**

6.6 The expectations that residents would fit into routines and norms of the LTCF conflicted with their innate desire to continue to be the individuals (i.e. maintain identity & personhood) they were before admission\textsuperscript{106}. (C)

- One resident commented: "Be kind and courteous; follow the rules ...." [P51]

- One former businessman was constantly critical that things were not done the "the right way." He tried to retain control and identity by not following the LTCF rules and keeping to himself. [P51]

7.4 Adapting to the LTCF including making the facility feel like home which included residents personalising their rooms and participating in enjoyable activities\textsuperscript{107}. (C)

- Residents knew in advance the type of possessions they were able to bring with them and they did so. [p384]

- New residents participated in activities which often reflected a continuation of life-long interest, (e.g. attendance at religious services, musical sessions, pubs, crafts and card playing) with the presence of other residents often a feature of the activities mentioned. [p384]

15.3 Links to the previous life through family and friends were important and home and possessions that held memories were held dear in the hearts and so these memory-object links were also important in influencing adjustment to the new living environment\textsuperscript{109}. (U)

- One individual shared: “The pieces I wanted were brought up here. I knew everything would fit. So my apartment I am happy with. It is, to me, very attractive and has my own favorite things. It meant sorting out and getting rid of a lot and saving some that I did not have the heart to get rid of. But anyway, my apartment is very pretty and that has a lot to do with me being happy here.” [P30] The home-like environment was conducive to inviting
guests. One woman remarked, “We can invite two guests for the meals, any meals. This way our children and grandchildren can come.” [P30]

- For some, there was not enough room. He stated: “I've built shelves and put things under the bed, but I still have more things [stored in his car] I can't part with, and I really hated to leave our Christmas tree behind.” [P30]

- Another participant commented, “I miss my friends in town. They can't get here, and I can't get there.” [P30]

- Many participants made new friends and felt “like a family” in their new location. “We watch out for each other, and I try to hold the elevator for those who need more time,” said one man. [P30]

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**Synthesised Finding 3**

*The ability to make valued decisions and to maintain links to people, places and objects from pre-facility life contributes to a sense of self and autonomy which is under continuous threat from the pressures to conform to LTCF norms and routines.*

The struggle for independence and normality was a consistent theme. People entering a LTCF are engaged in a struggle for independence and control over their life and as such central to a person's response to relocating to a LTCF was the degree of disruption the relocation had on that struggle. There is a conflict between a person's innate desire to retain control over their life and the expectation that people entering aged care would conform and fit to the routines and norms of the LTCF. Even older people who relocated voluntarily understood they needed assistance but were not prepared for the loss of decision making in their own life, the loss of independence and the reliance on staff, often expressing feelings of embarrassment, frustration or anger. The struggle for independence was difficult and was often reflected in choices around participation or non-participation in activities.

Part of the struggle involved trying to maintain activities, relationships and connections to the past that existed prior to the relocation to the LTCF. This connection to life prior to entering into the LTCF was linked to memories of home and the past which were associated with particular possessions brought to the LTCF to make it more homelike. The lack of room in the facility to bring possessions from home was a concern to some people. Relationships were important but
complex. Relationships with staff were coloured by the reality of dependency \(^{106}\), relationships with other residents reflected the interpersonal style of the person \(^{67, 108}\) and ongoing family relationships were important to a sense of connectedness \(^{67, 108}\).

Table 8: Summary of Evidence Credibility – Synthesised Finding 3

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>UNEQUIVOCAL</th>
<th>CREDIBLE</th>
<th>UNSUPPORTED</th>
<th>TOTAL</th>
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<tbody>
<tr>
<td>3.1</td>
<td>1</td>
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<td>3.2</td>
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<tr>
<td>3.3</td>
<td>1</td>
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<tr>
<td>TOTAL</td>
<td>4</td>
<td>5</td>
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<td>9</td>
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</table>
Synthesised Finding 4

People's process of acceptance or resistance to a LTCF relocation and their feelings and reactions to the move are complex and will differ dramatically both in the nature of the responses and the timing of those responses.

<table>
<thead>
<tr>
<th>Synthesized Finding</th>
<th>Category</th>
<th>Study Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.4 There was a sense of resignation and philosophical acceptance of the relocation to a LTC and most people said it is something they must endure as part of ageing. (U)</td>
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<tr>
<td>1.5 There were positive responses to the move largely associated with the opportunity to socialize with females expressing gains in social interaction. (U)</td>
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<tr>
<td>2.2 Acceptance may involve being realistic about the future and the acceptance of not returning home. (U)</td>
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<tr>
<td>4.2 A basic condition affecting the response to the admission was the perceived desirability of the move however the combination of the strong desire by elders for self-sufficiency combined with the negative image of nursing homes makes becoming a nursing home resident highly undesirable. (C)</td>
<td></td>
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<tr>
<td>4.3 An essential condition for the acceptance of a nursing home admission was legitimation which is the finding of a plausible reason for the admission that allows the resident to see themselves as other than a 'typical nursing home patient' and this requires that the elder participate in the decision making process, otherwise it is illegitimate and involuntary. (C)</td>
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<tr>
<td>4.4 The belief by the elder of the irreversibility of the relocation to the nursing home is a contributing factor to the acceptance or resistance to the move. (Unsupported)</td>
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<tr>
<td>4.5 A positive change to any of the conditions that produced resistance can lead to acceptance by what is called strategic submitting or submitting by default. (C)</td>
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<tr>
<td>4.6 Resistance to the nursing home can occur for a number of reasons and the resistance takes the form of either resigned or forceful resisting. Resigned resisting being characterised by a range of behaviours from brief withdrawal, crying and sadness to expressions of profound hopelessness and helplessness and these residents were described as giving up the will to live or just waiting to die. Forceful resistance characterised by behaviours ranging from angry silence, refusal to eat or receive care to verbal and physical abuse and elders expressed anger, betrayal or unjust treatment. (U)</td>
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<tr>
<td>11.1 There was a relationship between the ability to accept the decision, recognising legitimate reasons to move into a hostel, and a person's adjustment and motivation to become involved in hostel life. (U)</td>
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<tr>
<td>15.5 People moving into a LTCF recognized that it takes time to adjust to a new environment, but the length of time varied from person to person and could be as short as a week or continuous for months. Some found adjustment was eased by waiting to sell the house and others found it difficult to return to paying rents and paying for individual care services. (C)</td>
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<tr>
<td>16.3 The initial process of adjusting to a nursing home life requires work on the part of the older adult with those older adults who had not planned on entering a nursing home either taking longer to reach this acceptance stage or in some cases, not reaching it. (C)</td>
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<tr>
<td>People's acceptance or resistance to the relocation is complex involving such things as the decision process, establishing a plausible reason for the move, identifying there is no returning home or even rededdling themselves as dependent or ill.</td>
<td>Category 4.1</td>
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</table>

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### Diagram 5  Synthesised Findings 4

<table>
<thead>
<tr>
<th>Synthesized Finding</th>
<th>Category</th>
<th>Study Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.5 There were positive responses to the move largely associated with the opportunity to socialize with females expressing gains in social interaction. (U)</td>
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<tr>
<td>7.1 Residents will experience a range of emotional reactions during the first two weeks of their admission to a long term care facility (LTCF) and those reactions will change in relation to different aspects of the facility. (U)</td>
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<tr>
<td>7.7 In reflecting on their situation most residents were unable to describe their expectations of the LTCF and while &quot;It's different&quot; was a frequent observation the actual appraisals of the facility and their experiences ranged from disapproval to ringing endorsement. (U)</td>
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<tr>
<td>6.4 Residents’ emotional reaction to admission shifted over time from an initial sense of relief to one of suppressed dissatisfaction by 3 months. (U)</td>
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<tr>
<td>6.5 From 3 - 5 months residents reappraised their circumstances within the LTCF with most expressing dissatisfaction at how their current expectations were met. (U)</td>
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<tr>
<td>8.1 There were a range of emotional responses expressed arising from the admission with some residents being positive and feeling &quot;safe at heart&quot;, while at the others felt frightened and uneasy or had feelings of being powerless with a wish to die. (U)</td>
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<tr>
<td>16.1 For many, the initial response to the nursing home was the expression of feelings of loneliness, sadness, crying, being afraid and experiencing a sense of loss and this was particularly so for people who experienced unplanned admissions and issues such as limited communication with family and friends, lack of privacy and space made the transition more difficult and yet the older adults were reluctant to discuss these emotional responses with their families. (U)</td>
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<tr>
<td>15.4 Some residents found the move to the assisted living facility to be positive as it provided welcomed social interaction and enabled new and affectionate relationships while for other residents the move proved difficult because they were used to living alone while others found living with people with dementia difficult. (U)</td>
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</table>

**People’s reactions to relocation differ significantly (e.g. a sense of relief, enthusiasm, anger, loneliness, betrayal) and these reactions may also change dramatically over time (e.g. change from relief to dissatisfaction).**
Category 4.1 People's acceptance or resistance to the relocation is complex involving such things as the decision process, establishing a plausible reason for the move, identifying there is no returning home or even redefining themselves as dependent or ill.

Findings in this category:

2.2 Acceptance may involve being realistic about the future and the acceptance of not returning home\textsuperscript{112}. (U)

- George: "...I am used to being here, I have to put it on myself that I am here. I have got my mind made up that the rest of my life will be spent here, or a place like this. I won't [pauses], I will never be well enough now." [p8]

4.2 A basic condition affecting the response to the admission was the perceived desirability of the move however the combination of the strong desire by elders for self-sufficiency combined with the negative image of nursing homes makes becoming a nursing home resident highly undesirable\textsuperscript{69}. (C)

- To accept admission may mean that elders view themselves as unwanted, dependent, near to death - or worse, senile. [p68]

4.3 An essential condition for the acceptance of a nursing home admission was legitimation which is the finding of a plausible reason for the admission that allows the resident to see themselves as other than a 'typical nursing home patient' and this requires that the elder participate in the decision making process, otherwise it is illegitimate and involuntary\textsuperscript{69}. (C)

- Once the reason for the admission was explained and accepted by the elder, entry to the nursing home was legitimated and the move could be made voluntarily because the elder had accounted for it in his or her self-perception. [p94]

- A woman newly admitted to a nursing home. "I fall many times at home. I begged my daughter not to call the ambulance. I was not hurt [after the fall]. I was so mad when I heard the ambulance come." [p94]

4.4 The belief by the elder of the irreversibility of the relocation to the nursing home is a contributing factor to the acceptance or resistance to the move\textsuperscript{69}. (Un)

- When irreversibility was combined with undesirability, lack of voluntary participation, and no legitimation the elder resisted. [p94]

4.5 A positive change to any of the conditions that produced resistance can lead to acceptance by what is called strategic submitting or submitting by default\textsuperscript{69}. (C)

*Example of submitting strategically*

- Some elders focused their energy on making a life in the nursing home
continuous with their past life. A former executive secretary posted the facility newsletters, was active on the residents' council and served as the informal receptionist on weekends. [p94]

Example of submitting by default.

- Residents shifted focus to another, usually catastrophic, life event. Mrs C entered a nursing home 2 months after the death of her husband. She focused almost exclusively on the loss of her husband and home for months after the admission. [p95]

4.6 Resistance to the nursing home can occur for a number of reasons and the resistance takes the form of either resigned or forceful resisting. Resigned resisting being characterised by a range of behaviours from brief withdrawal, crying and sadness to expressions of profound hopelessness and helplessness and these residents were described as giving up the will to live or just waiting to die. Forceful resistance characterised by behaviours ranging from angry silence, refusal to eat or receive care to verbal and physical abuse and elders expressed anger, betrayal or unjust treatment.

<table>
<thead>
<tr>
<th>Resigned Resisting</th>
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<tbody>
<tr>
<td>Ms D packed her bags every day for several weeks after admission. She would then sit in her room, weeping quietly. Family members &quot;I thought you said my mother would be happy here.&quot; or &quot;What do I do when my father won't speak to me when I visit?&quot; [p94]</td>
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<tr>
<th>Forceful Resisting</th>
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<tr>
<td>&quot;They can make me stay here. There's no way for me to leave in my condition now, but they can't make me be nice. I've been a lady all my life and it's brought me to this. I will show them. They will know I do not want to be here.&quot; [p96]</td>
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<tr>
<td>Mr G a 90 year old with terminal cancer, complained about the staff, screamed at them, refused to eat or use his call bell. [p96]</td>
</tr>
</tbody>
</table>

11.1 There was a relationship between the ability to accept the decision, recognising legitimate reasons to move into a hostel, and a person's adjustment and motivation to become involved in hostel life. [113] (U)

- (Participant 2) "I think you make your decision, if and if you're going to run away from it all the time, you'll never settle down." [P126]
- (Participant 4) “It's a case of adjustment, and adjustment may take you a while. I get impatient sometimes, but I couldn't be anywhere else because I need the care ... I couldn't cope at home. So while I miss it ... it can't be any other way ... it just can't.” [P128]
- (Participant 4) “I didn't have time to think about it ... see, I wasn't well, and you don't think straight when you are not well. I hadn't really given it a lot of thought ... so it came as a bit of a shock to the system ... I guess it's probably not unusual for me to say that I wasn't happy, and I'm still not
happy.” [P128]

- Having the control over their life over-ridden by being “shoved in” to hostel care can make it more difficult to accept the changes: (Participant 10) “I'm not silly. I know that everyone has their life to lead, but I wish that they would understand that I want to lead mine too, and this is not letting me lead my life ... See, everyone know what's best for you, but they never ask you ... It's not what I want at all, it's what they want ... . It's very hurtful, very hurtful.” [P128]

- The majority of the residents were able to recognise the necessity, and even the advantages of relocating.[P128]

15.5 People moving into a LTCF recognized that it takes time to adjust to a new environment, but the length of time varied from person to person and could be as short as a week or continue for months. Some found adjustment was eased by waiting to sell the house and others found it difficult to return to paying rents and paying for individual care services. (C)

- When talking about the adjustment time, one participant stated: “It is a matter of attitude. If you decide that it is an adventure, the next stage in life, then you accept it and go on from there.” [P30]

- Some didn't miss the upkeep and repairs of their home but felt it seemed so expensive to make monthly payments. They also found it difficult to adjust to paying for individual services such as medication distribution, assistance with personal hygiene, and bandage changing. [P30]

16.3 The initial process of adjusting to a nursing home life requires work on the part of the older adult with those older adults who had not planned on entering a nursing home either taking longer to reach this acceptance stage or in some cases, not reaching it. (C)

- One woman who had planned nursing home admission commented: “Nobody can help me but myself. You've got to pick up your boots and do it. As long as I can keep my sense of humour and keep walking it should be all right. It's starting to be more like home. [P869]”

- Similar another women with a planned admission commented: “I'm trying to get myself oriented instead of sitting up here and sulking. I am trying to get involved in things. That's the only way you can get yourself out of the doldrums. So I better get on with it and not sit around and feel sorry for myself.” [P869]

- Two older adults in the unplanned group did not reach the acceptance phase. Both remained in their rooms, had little contact with other residents and continued to display negative emotional responses. [P869]
Category 4.2 People's reactions to relocation differ significantly (e.g. a sense of relief, enthusiasm, anger, loneliness, betrayal) and these reactions may also change dramatically over time (e.g. a change from relief to dissatisfaction).

Findings in this category:

1.4 There was a sense of resignation and philosophical acceptance of the relocation to a LTC and most people said it is something they must endure as part of ageing\textsuperscript{105}. (U)

- Andrew: “I don't feel good about it!... We'd a hundred precent rathered stayed at home... It wasn't our desire to be here. We didn't think we deserved it. We don't have anything against this place ... We would recommend this place to anybody. We're gonna live the best we know how...be ready when the Lord comes.” [p90]

- Beatrice “Well, I knew i was going to have to.... I've had a full life.” [p90]

1.5 There were positive responses to the move largely associated with the opportunity to socialize, with females expressing gains in social interaction\textsuperscript{105}. (U)

- Beatrice: “Oh, I wouldn't have done all this at home (participation in a social competition at the facility). I was glad that I won something for the nursing home. I'm looking forward to that (planned future activity). And I do go to all the activities that I can.” [p90]

- Andrew: “… there are 3 people here I went to grade school with!” [p90]

7.1 Residents will experience a range of emotional reactions during the first two weeks of their admission to a long term care facility (LTCF) and those reactions will change in relation to different aspects of the facility\textsuperscript{107}. (U)

- A sense of relief was common: "This is far more preferable than living alone. I get awfully tired of living alone...It's so nice not to worry about meals ... Somebody stays with me when I'm in the tub. I like that. I don't worry about falling or getting short of breath.” [p383]

- Feelings of sadness, depression, anger, powerlessness and betrayal were expressed by four residents who felt they had no choice about their admission. "So at the end of my life you had to settle for this -- not that I lay awake about this but I do think it gets you very much down.” [p383]

- A 96 year old who had spent her life in the same small town "A very big shock. A younger person wouldn't understand it. I can't say that I ever felt worse in my whole life time. Really, I don't recall ever feeling this way before.” [p383]

7.7 In reflecting on their situation most residents were unable to describe their expectations of the LTCF and while "It's different" was a frequent observation the actual appraisals of the facility and their experiences ranged from disapproval to ringing endorsement\textsuperscript{107}. (U)
Disapproval was expressed in a number of ways. One woman had a list of shortcomings of the facility that included creaking bed springs, having to ask for medications, being in a 3 bed room and not seeing her doctor. Another commented "The food is fair. I wouldn't say OK." While another commented "You've got to be prepared to be one with the crowd. There are no special favours to speak of." [P386]

Guarded approval was reflected in such comments as "I wouldn't say anything against it." or "I wouldn't complain." [P385]

Positive comments included "This is a pretty good place." [385]

Enthusiastic endorsement included "I've never come across anybody more angelic than these nurses ... God bless her, she brought what I love [food]. I couldn't believe it. I've got a life now that I never thought was possible." [P385]

6.4 Residents' emotional reaction to admission shifted over time from an initial sense of relief to one of suppressed dissatisfaction by 3 months 106. (U)

An initial comment from one resident: "I couldn't get help and quick attention at home because I was alone." After three months several residents expressed their dissatisfaction. [P50]

One resident coped by not reacting: "Just keep your cool .... don't get uptight." [P51]

Another stated, in relation to staff routines: "They have some idiots running around at night checking out [the residents] ..... It's so idiotic. I don't know who runs this place, but there isn't much brains attached to it as far as I'm concerned." [P51]

6.5 From 3 - 5 months residents reappraised their circumstances within the LTCF with most expressing dissatisfaction at how their current expectations were met 106. (U)

One resident wishing to maintain his independence commented: "The staff are too helpful ... The best thing to do is to be ready to help, but don't do anything unless you're asked to do it." [P51]

In relation to staffing another resident commented: "They rotate staff and that's the problem ... You just get somebody used to what you want and then they're gone and you have to start all over again." [P51]

Another resident was cynical about the possibility of improvement. "It certainly isn't what it's all cracked up to be ... I just live a day at a time ... try to accept it .... there's quite a few things that need to be straightened out ... We have a Resident's Council ... that's a phony .... nothing happened from it. [P51]

One resident was happy from the beginning and at 9 months remarked: "I had a good feeling ever since I came here. I realize now I did the right thing." [P51]
8.1 There were a range of emotional responses expressed arising from the admission with some residents being positive and feeling "safe at heart", while others felt frightened and uneasy or had feelings of being powerless with a wish to die. (U)

- "I have nothing to worry about anymore, I just feel happy. I have someone to be with me and it's even better than being alone at home." [P1121]

- "Seeing how those sick residents suffer." as one resident commented contributed to being freighted and uneasy in the new environment. [P1121]

- "I am very very unhappy about the present situation. What can I say? I really have no choice. To be alive is really gloomy. I have no interest in my life anymore." [P1121]

15.4 Some residents found the move to the assisted living facility to be positive as it provided welcomed social interaction and enabled new and affectionate relationships while for other residents the move proved difficult because they were used to living alone, while others found living with people with dementia difficult. (U)

- One participant stated: “The help here is all very concerned for you and the people, the residents. If anyone hurts, the rest of the people feel it too.” [P30]

- One woman commented: “There are a lot of people around here whose minds are not very good; they don't belong in assisted living anymore. At the dinner table, they don't mind their manners. One lady uses the tablecloth to wipe her nose.” [P30]

16.1 For many, the initial response to the nursing home was the expression of feelings of loneliness, sadness, crying, being afraid and experiencing a sense of loss and this was particularly so for people who experienced unplanned admissions and issues such as limited communication with family and friends, lack of privacy and space which made the transition more difficult, yet the older adults were reluctant to discuss these emotional responses with their families. (U)

- One woman whose admission was unplanned cried when she talked about her family and being separated from them: “I get awful lonely and depressed. I wish I could be home. I forget a lot of things, my mind isn't working the way it should. I go to a room and forget why I went there. I'm afraid if I leave my room I'll get lost and won't find my way back. I don't want to be a burden to my daughter and her husband.” [P866]

- One woman talked about the lack of privacy: “You know people just come in this room. The door is open and they just walk in. I woke up Saturday morning and a man was standing by my bed. I don't care for that.” [P867]

- One person who planned to come to a nursing home commented: “When I first saw this room I cried. It was a shock, when you have a home of your own and an upstairs with bedrooms. Now you have to limit yourself to such a small space. But it doesn't look bad now [has several pictures from home and a favourite cuckoo clock]. The only thing bad about it is the
Synthesised Finding 4

People's process of acceptance or resistance to a LTCF relocation and their feelings and reactions to the move are complex and will differ dramatically both in the nature of the responses and the timing of those responses.

A person’s acceptance of being in the LTCF may involve being realistic about the future and not returning home or being able to assign a plausible, legitimate reason for the move that does not involve identification as a typical LTCF resident. Involuntary relocations retained a sense of illegitimacy and this was a barrier to acceptance of the move. A lack of acceptance to the relocation may be expressed as either a forceful resistance or a resigned, passive resistance to life within the LTCF.

Adjustment to the LTCF, even for voluntary relocations, required an effort on behalf of the person but the adjustment period was not predictable with some people adjusting within a week, others over months and for some there was never an adjustment, particularly for involuntary relocations. For some people, even those relocating voluntarily, the adjustment was accompanied by a sense of resignation or a philosophical acceptance while for others, particularly women, there was a positive response in relation to the opportunities to socialize.

There were a range of emotional reactions to the initial admission, even for voluntary relocations, which varied even in relation to different aspects of the facility and the responses continued to vary over time. For many who entered the LTCF involuntary the initial emotional responses were of loss, fear, loneliness and sadness with frequent episodes of crying. Most residents were not able to describe their expectations in relation to the LTCF and found it to be “different” with initial appraisal ranging from disapproval to ringing endorsement, however after 3 – 5 months most people expressed a sense of dissatisfaction at how their current expectations were met.

Summary of Evidence Credibility – Synthesised Finding 4

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>UNEQUIVOCAL</th>
<th>CREDIBLE</th>
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<tr>
<td>4.1</td>
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Table 9: Summary of evidence credibility - synthesis finding 4
Synthesised Finding 5
The challenges of learning how to live in a LTCF and of making a new life are significant and difficult requiring substantial effort on the part of the older person.

<table>
<thead>
<tr>
<th>Synthesized Finding</th>
<th>Category</th>
<th>Study Findings</th>
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<tbody>
<tr>
<td>5.2 About 1 to 2 months after admission residents told stories of getting settled which was reflected in the relational activities of getting to know people and becoming known and the difficult task of learning the ropes. (U)</td>
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<td>7.6 Most people had no expectation that the LTCF would adapt to them and they took an active part in learning and accepting the rules and norms as part of the fitting in aspect of transition. (U)</td>
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<td>6.2 Fitting into the LTCF was mainly related to accepting and adapting to institutional routines and following staff's instructions as well as participating in activities. (U)</td>
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<td>8.2 Most people considered it not a problem to live together with other 'strangers'. (U)</td>
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<td>8.3 The newly admitted residents were cautious in establishing new relationships with other residents and staff. (U)</td>
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<tr>
<td>9.1 The first 2 weeks to 1 month immediately after admission is an orienting stage where newly admitted elders use their own efforts to gain a realistic understanding of the dynamics of every aspect of the nursing home including both the written and unwritten rules. (U)</td>
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<tr>
<td>9.2 From around the third or fourth week to the fifth month after admission most newly admitted elders entered a normalizing stage as they attempted to maintain a lifestyle close to that before admission however none were able to re-establish life as ‘normal’ as before admission. The findings suggest that the elders’ normalizing to life within the nursing home follows a temporal sequence of; thoroughly work through the rules and regulations, getting through communal living, establishing interpersonal relations with other residents and staff and finally dealing with altered family relations. (C)</td>
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<td>13.3 Shared geography formed the basis of initial conversations with fellow residents in the initial period after the move which formed the basis of more permanent relationships or helped as a ‘springboard’ for other relationships while a lack of shared geography may act as an initial barrier to social engagement as there was no shared belonging. (U)</td>
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<td>3.2 A reorganization phase generally occurred in the 2nd or 3rd month and was characterised by the challenge to find meaning in the experience of living in a nursing home and involved residents in problem solving, identifying preferred care and resolving or justifying why they live in a nursing home. (U)</td>
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<td>Synthesized Finding</td>
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<tr>
<td>3.3 The third, relationship building phase began around the third month which was characterised by forming relationships, showing preference for particular people, engaging in conflicts with other residents and staff and experiencing a sense of loss when another resident dies or a staff member leaves. (C)</td>
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<td>3.4 The fourth, stabilization, phase, generally happened within 3 to 6 months of admission and the challenge in this phase was conforming while maintaining self-identity. (C)</td>
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<td>5.3 Creating a place, often with an attitude of making the best of it, was a theme that usually began to emerge after 2 to 3 months as residents’ conversations began to take on new possibilities as new meanings were being created. (U)</td>
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<td>7.8 The philosophy of life or belief system of the residents who were ready to be admitted seemed to help them make sense of their lives and current situation while similar statements were not reflected by residents who resisted admission. (C)</td>
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<td>9.3 To come to terms with and put their lives back together elders used a rationalizing process that included the strategies of protecting the face, softening the blow, and defining the nursing home. (C)</td>
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<tr>
<td>9.4 After all the efforts directed toward regaining normality at around 5 to 6 months after admission, most residents began to enter this final stage of the adjustment process where they started to reconstruct what it should be like being old and in a nursing home. The central theme thus identified was resignation from previous life: to be simple, peaceful, take things easy, eat, and rest more. (U)</td>
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<tr>
<td>11.3 Participants frequently emphasised the importance of social interactions and relationships for facilitating their emotional adjustment to hostel life. Many participants felt that adjustment was related to &quot;the feeling of being accepted by other residents&quot;. (Participant 9) (U)</td>
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<tr>
<td>11.4 Participation in meaningful and productive activities was described by participants as being vital to achieving successful adjustment and a sense of well-being and for some participants who felt that the hostel environment limited their occupational engagement experienced their adjustment as difficult. (U)</td>
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<td>16.2 As part of the adjustment process older adults begin to internalize the nursing home admission thinking about the future and everyday living not withstanding concerns relating to control and autonomy. They also try to have a positive attitude and established new social networks. (U)</td>
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Diagram 6 Synthesised Findings 5
Category 5.1 Older people have the challenging task of learning a radically different way of life, learning a new geography and learning rules of both the new land (the facility) and the new social (peers and staff) environment.

Findings in this category:

5.2 About 1 to 2 months after admission residents told stories of becoming settled which was reflected in the relational activities of getting to know people and becoming known and the difficult task of learning the ropes.

Learning the ropes

- In relation to learn how to negotiate the maze of the new facility and unfamiliar staff John commented: "You've got to learn the ropes. Nobody tells you anything." [p38]
- Robert found the room numbering difficult to understand; "People change things around, putting it down, and I don't know where they put it." [p38]
- One resident noted of staff, “It's so routine. They have their duties and that's it.” [p39]
- Herbert sadly noted, “I'm a prisoner here.” [p39]
- Helen remarked “I went to the beauty shop, and they lined us up in the hall, and we waited for our hair to be fixed. Well, I ain't going no more. I'm not allowed to go to my own beautician. I've been making decisions since I was 15 years old but here” [p39]
- Another resident, Mary, noted: “In the dining room, they like you to have your own place. You can't change places, and they have rules. You can't do this; you can't do that.” [p39]

Becoming Known and Knowing Others

- Robert had this advice: "Just be friendly to these people, and they'll be friendly to you. Just be good to them, and they'll be good to you.” [p39]
- Herbert said, “They're [staff] out there, and I'm in here. I'm isolated.” However, he added “I'm acquainted with all these nurses down here. They like me and I like them. Cook's the same way. She always has a little ice cream for me.” [p39]
- Another resident noted, “Service is good...but you don't know what they’re [staff] thinking, and they don't know what I'm thinking.” [p39]

7.6 Most people had no expectation that the LTCF would adapt to them and they took an active part in learning and accepting the rules and norms as
part of the fitting in aspect of transition\textsuperscript{107}. (U)

- One woman explained "This is what you have to do - fit in - and be flexible ... and don't let your feelings get hurt." [p385]

- Another woman explained "You have to live by the rules and regulations of the place and the girls that are looking after you." [P385]

- Residents identified the consequences of not complying with the rules or schedules. "It's [food] put on their table the same time as the rest of us and if they're not there with the rest of us, they get their food cold." [P385]

- Shared bathroom facilities was a concern to many of the female residents. One stated "the biggest thing worrying me is the lack of privacy ... your life is like an open book." To cope with this one woman bathed early in the morning so she could have privacy while still following the routine of the morning bath. [P385]

6.2 Fitting into the LTCF was mainly related to accepting and adapting to institutional routines and following staff's instructions as well as participating in activities\textsuperscript{106}. (U)

- At 2 weeks one resident said "Just try to work out the system and not go against it because the system is good and it's proven that it's good ... just go along with it, otherwise you're going to run into a lot of problems caused by you." [P47]

- At 9 months, another resident remarked about the lack of individualized care: “You have to conform with the rules,” and at 12 months, his advice to a newcomer was, “Tuck your pride away and do as you're told.” [P47]

- One resident attended ceramic classes making gifts for his family. He particularly like that "guy down there lets me do what I want." Another resident was able to fit into the LTCF without much interaction by playing the piano. "I'm busy with ... music ... You block yourself right off from what's around you.”[P50]

8.2 Most people considered it not a problem to live together with other 'strangers'\textsuperscript{115}. (U)

- "We are eating together and therefore this is not a personal matter. I would say the food here belongs to everybody. How can this home cater [for]the needs of everybody? Therefore, you may sometimes have your favourite food but not always. Anyway, the meals are different every day. I have no problem with this at all." [P1122]

- The only elder who was troubled by the communal living commented: “You must know that there are about eight of us sharing three toilets, we need to schedule our time in using the toilets. I am not used to wait outside the toilets. I am also afraid that I may not be able to hold. Also, at home, I bathe in the afternoon just before dinner. Yet, people here bathe in the afternoon too. It's so crowded and the water is not hot enough! What's the point? I therefore changed to bathe in the morning. But I am afraid of getting a cold, it's so cool in the morning and I am not used to that.”
Residents accepted the need to comply with the rules and regulations and saw this as part of communal living. As one resident commented: “The staff here are already very busy looking after us. I don't want to bother them and I think it's reasonable that we had to sacrifice our own needs in order to accommodate the demand of communal living.”

8.3 The newly admitted residents were cautious in establishing new relationships with other residents and staff. (U)

"It's really difficult for me to talk to others, I don't really know who they are and how they perceive me. They might not want to talk to me too!" [P1123]

"We chat in a large group, in the morning and night-time. We got nothing more than that. That's it. It's important not to be too involved in these relationships.” [P1123]

Relationships with staff were also superficial and distant. Some residents felt very sad as they thought they were misunderstood by the staff. "I just wanted to have a bedside commode because my leg aches and you see that I cannot walk properly. I am afraid of not able to get to the toilet on time ... I don't want to be like that. I have my dignity too (sigh)! But they (the staff) thought I was being lazy and don't want to be independent." [P1124]

9.1 The first 2 weeks to 1 month immediately after admission is an orienting stage where newly admitted elders use their own efforts to gain a realistic understanding of the dynamics of every aspect of the nursing home including both the written and unwritten rules. (U)

“Ms.Ho [the deputy superintendent] told me not to hang dry my clothes in the corridor. Yet, I saw a lot of others were doing this in the evening. I just informally checked this with Ah Mei. I now know that this rule is really not followed. The staff would ‘close one of their eyes’ and just let us dry our clothes in the evening. We could not do this in the morning. They [the staff] say that this is too unsightly!”[P671]

New residents identified those other residents upon whose “toes” they did not want to “tread” (labelled as the “kings” and “queens”). [P671]

9.2 From around the third or fourth week to the fifth month after admission most newly admitted elders entered a normalizing stage as they attempted to maintain a lifestyle close to that before admission, however none were able to re-establish life as ‘normal’ as before admission. The findings suggest that the elders' normalizing to life within the nursing home follows a temporal sequence of; thoroughly work through the rules and regulations, getting through communal living, establishing interpersonal relations with other residents and staff and finally dealing with altered family relations. (C)

All residents obeyed the rules and regulations and attempted to fit in by repatterning their lifestyles and daily routines as much as they could as they
regarded rules and regulations as the “laws of a country” and as necessary in maintaining harmony and order in the nursing home. [P679]

• Several residents referred to the Chinese proverb "Follow the culture wherein you live." in relation to communal living. [P240 (a)]

• “If there is a vacancy in the bathroom, you can go ahead to take a bath. If the bathrooms are fully occupied, you have to wait until others had finished. It is the same as living at home...you also have to take turns for bathing. Now, you just live in a bigger room with more neighbours.” [P671]

• [P671] Residents were cautious in dealings with other residents and staff. Stories of “difficult residents” were abundant and resulted in unresolved turmoil, suffering and unhappiness. None of the residents attempted to inform the staff of these incidents as the staff were seen as the “rulers of the country” and as one resident commented “They (staff) should know of these problems, I really don’t know how to tell them.”

• Of all the aspects of normalizing, working through the altered family relationship was considered by the elders as the most difficult. This was a result of Chinese cultural characteristics that strongly emphasized family ideology. In order to re-establish their lives in-side the new home, elders rationally worked to let go of their emotional attachments to the families by discouraging their families from visiting them. They also disguised their feelings about problems of settling into the nursing home. This, however, raised intense feelings of ambivalence in the elderly residents. [P671]

13.3 Shared geography formed the basis of initial conversations with fellow residents in the initial period after the move which formed the basis of more permanent relationships or helped as a 'springboard' for other relationships while a lack of shared geography may act as an initial barrier to social engagement as there was no shared belonging\textsuperscript{10}. (U)

• One participant said: "I got talking to a couple of people that I recognised from around the village, and that helped, I felt settled. Then when I'd found my feet I got to know some more people that I didn't know before".[P865]

• One participant, for example, said of another resident, "She doesn't belong here, she belongs over X (a nearby town), so I don't know anything about her, I can't place her. The other women, mind, I know her, she used to live up Y street".[P865]

\begin{table}[h]
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\begin{tabular}{|l|}
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\textbf{Category 5. 2} Residents who established a sense of a new life within the LTCF were able to accept the future of life within the facility, fit in and accepted the routines of the facility, make new relationships and establish meaningful activities. \\
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Findings in this category:

3.2 A second reorganization phase generally occurred in the 2nd or 3rd
month and was characterised by the challenge to find meaning in the experience of living in a nursing home and involved residents in problem solving, identifying preferred care and resolving or justifying why they live in a nursing home. (U)

- "If I stay here it gives my daughter a chance to go on vacation"[p67]
- "I helped my wife by moving here, she was becoming ill caring for me. It was either her or me." [p67]
- Residents began to ask more questions, complaining about the limited space, explaining needs to new staff, etc. [p67]

3.3 The third, relationship building phase began around the third month which was characterised by forming relationships, showing preference for particular people, engaging in conflicts with other residents and staff and experiencing a sense of loss when another resident dies or a staff member leaves. (C)

- Referring to a staff member: "He said I stunk. Well, I wasn't going to let him give me a shower after that. These teenagers think I have to put up with them." [p68]
- Loss of a favourite staff member caused distress. Resigning staff often seemed to disappear without terminating established relationships. [p67]
- Making friends with other residents is crucial since a friend allows one to cheerfully exchange complains and fears. [p67]
- Loss of recently established friendships through death or disability frequently brought emotional pain. [p67]

3.4 The fourth, stabilization, phase, generally happened within 3 to 6 months of admission and the challenge in this phase was conforming while maintaining self-identity. (C)

- A stabilized resident noticed things and was more often aware of the complex environment than staff realised. The awareness included recognizing the future and feeling a little uncertain. "I didn't have the reserve for the future. I feel a little more sad. I recognized what is happening to me. Living here is like living on the edge." [p68]
- Residents were more secure with changes as long as the changes did not interfere with established routines, threatened stability or involved loss of favourite personnel. "When you're old, the outside world gets too much. It's nice to have people to lean on." [p68]

5.3 Creating a place, often with an attitude of making the best of it, was a theme that usually began to emerge after 2 to 3 months as residents' conversations began to take on new possibilities as new meanings were being created. (U)

- Helen commented in relation to being asked to move to another room. “They wanted me to move upstairs. NO WAY! This is a private room. Upstairs there are all two-bed rooms. I don't want to share my family with
others. I like this private place. This place is mine.” [p40]

- When asked how she saw “this place,” Helen hesitated and then said, “It's not like home. There's no place like home, but I don't know what I'd do without the help here.” [p40]

- Mary knew she was not home, but in a place that was reliable, safe, and met her basic needs. Within 2 months, Mary said: “I have a place to lay my head down at night and three meals a day, and a van gets me to church on Sunday, and so I'm just thankful.” [p40]

- "I'm uncomfortable all the time ... but I try to make the best of it." [p40]

- Betty "I made up my mind to go ahead with what I can do. We have to play the cards we are dealt." [p40]

7.8 The philosophy of life or belief system of the residents who were ready to be admitted seemed to help them make sense of their lives and current situation while similar statements were not reflected by residents who resisted admission[^107]. (C)

- Comments included: "It's God's will."; "Life is what you make it."; "You have got to go halfway."; "I have a lot to be thankful for and will make the most of it. I like to have a nice attitude wherever I am and a smile on my face." [P385]

- Such statements were not made by those residents who felt powerless in the decision making about their admission. They apparently were so shocked and dazed, or so consumed by feelings of anger, that they could focus only on the process that led to the admission. [P385]

9.3 To come to terms with and put their lives back together elders used a rationalizing process that included the strategies of protecting the face, softening the blow, and defining the nursing home[^107]. (C)

- Due to the Chinese virtue of filial piety there was a loss of face associated with nursing home admission and elders had to struggle to protect their own "face" and that of their families. "I won't let others know that I have come and stayed here. I told my son to tell others that I was now living with my daughter. Only then will those people shut their mouths if they know that my son has not abandoned me.” [P671]

- As elders realized they could not manage as they wished they began to soften the blow by downplaying the negative so as to make day-to-day life. They attempted to validate their problems with other residents, relate them to old age or simply ignore them. One elder explained this: “Hey, you can just sit over here for a while and you can hear how some of them [other residents] are talking about missing who and who. We are all like that. It is only abnormal if you don't miss someone or something. You are starting a new life here.” [P672]

- Having softened the blow most elders redefined the nursing home as their “second home”. Almost like home except they were not living with their families.[P672]
9.4 After all the efforts directed toward regaining normality at around 5 to 6 months after admission, most residents began to enter this final stage of the adjustment process where they started to reconstruct what it should be like being old and in a nursing home. The central theme thus identified was resignation from previous life: to be simple, peaceful, take things easy, eat, and rest more. (U)

- Reflecting on how he was being accused of not flushing the toilet by the “king” who had threatened to kill him, one elder remarked: “Maybe we were enemies in our lives previous to this. I might have treated him badly then and now it's his turn to take revenge. Maybe, it's just all what it is about. It's fate that brings us here in this very same nursing home! I have to accept this.” [P672]

- Most residents also started to formally connect themselves to the nursing home life participating in organized activities and getting more involved with people around them. [P672]

- In fact, there was a strong desire evident among the elderly residents in this study not to be a burden on their families. They were very rational in describing the need to let go of emotions with the families so as to re-establish their lives in the new home. They discouraged the families from visiting them and disguised their feelings as regards problems of settling in. Yet, this brought them intense feelings of ambivalence. [P242 (a)]

11.3 Participants frequently emphasised the importance of social interactions and relationships for facilitating their emotional adjustment to hostel life. Many participants felt that adjustment was related to “the feeling of being accepted by other residents”. (Participant 9) (U)

- Many participants suggested that mixing with people was the most difficult thing to adjust to: "After having been on your own for a while ... you definitely feel like a square peg in a round hole ... but then you start to get to know the other people, to talk to them, and you start to fit in.” [P129]

- Participants frequently described the importance of being involved in group activities but for some this was difficult and limited their ability to adjust. “I'm gradually getting acclimatised to it ... as I feel that I can associate with some people without making a fool of myself ... I would get to know people better if I was in the big room watching TV, but I'm not ready for that ... so my adjustment is still to come I think.” [P129]

- Participants also emphasised the importance of “comradeship” (Participant 9), and “helping each other out” (Participant 1). Participant 9 stated that “it was very useful for me to overcome my grief by helping other people ... and I felt great”. [P129]

- Other participants found it difficult to adjust because they felt like they did not belong: (Participant 10) “I have tried very, very hard to settle down and fit in, but I can't because I'm a different person ... I just don't fit in here. It's not my life. It's very hard at my age to alter your personality, and that's what I'm trying to do.” [P129]
11.4 Participation in meaningful and productive activities was described by participants as being vital to achieving successful adjustment and a sense of well-being, while some participants, who felt that the hostel environment limited their occupational engagement, experienced their adjustment as difficult. (U)

- One participant who was able to participate in activities commented: “I feel like I am still doing some normal things in life ... and that's the way I like it ... I think but doing that it's good for my mind. It's sort of like the things I did before, that life hasn't change that much, it's just got a bit slower.” [P129]

- Most residents did not feel that the rules and regulations were restricting in relation to the control over their life: "you know that there has to be rules ... and you conform, but they don't force you. It's your own common sense that tells you”. (Participant 9) [P129]

- Others felt the regulations limited their occupational choices: "I always felt that when I got to this age, I would go to bed when I was tired, I would get up when I was refreshed, I would eat when I was hungry, and go out when I wanted to go out.”(Participant 10) [P129]

- The majority of participants felt there were sufficient opportunities for meaningful occupational engagement. Participant 1 commented that the hostel was “better than I thought it would be because I didn't have visions of having things arranged for you to do.” [P130]

- Other participants felt that the occupational opportunities were not ideal for them and these residents found adjustment more difficult: Participant 8 stated: “I have always been active, and then suddenly dumped here, 24 hours a day, with nothing to do ...I feel as if I want to get out and do something ... It's driving me mad, I mean there is nothing to do, no-one to talk to.” And participant 11 commented in relation to activities such as poetry and bingo “I don't play child's games. I am not a child anymore.” [P130]

16.2 As part of the adjustment process older adults begin to internalize the nursing home admission thinking about the future and everyday living notwithstanding concerns relating to control and autonomy. They also try to have a positive attitude and established new social networks. (U)

- “You have to have a positive attitude. It's all in your disposition, you know. If you are going to be a grouch, be one, but it doesn't hurt to give someone a smile and talk to them.” [P868]

- “Some people adjust to it and some can't. It's not easy. It's different than living in your own home. You have to learn to like it.” [P868]

- Establishing new social networks was difficult for many of the older adults. “If there was someone I could get acquainted with it would be easier to get adjusted. These people are really old, I think they are all in their nineties. They are too old to play cards with and some of them are pretty far gone.” [P868]
The rules and regulations of the nursing home were a problem: “You know what it is here? One word? Regimentation. You have to report for everything and they have control over everything. You have to sign in and sign out. They tell you what you can have and what you can’t have. Do you know what they did when I came here? They took my purse and went through it without asking me. I know when you go to a hospital they ask you if you have pills with you. But here, plain and simple, they took my purse away from me. They had everything I had in my purse. All my medications.” [P868]

Other concerns were expressed about nursing home rules: “There's so many rules and regulations. You can't go here, you can't go there. You've got to do this, you've got to do that. That's not how my life has been.” [P868]

Synthesised Finding 5

The challenges of learning how to live in a LTCF and of making a new life are significant and difficult requiring substantial effort on the part of the older person.

On entering a LTCF most people accepted that the facility would not adapt to them and so they are faced with the challenge of learning the rules and norms of the facility. This was an individual learning challenge with new residents having to use their own efforts to discover the dynamics of the facility and learn both the written and unwritten rules. As well as learning the way of a new 'land' new residents also had to enter a new social world and faced the challenge of getting to know people and becoming known. Most people did not find it a problem being with other 'strangers' in the facility but were cautious about establishing new relationships with them, whether they were residents or staff. A shared belonging to a particular geographic area can provide a basis for initial conversations which may lead to more permanent relationships or be a link to other relationships. Within the facility people generally formed new relationships but there were also indications of conflicts with other residents or staff however the new relationships also brought new experiences of loss as other residents died or staff left.

In addition to getting to know the new land and the new people there is the challenge of maintaining a sense of identity and finding a new sense of purpose and meaning. People who were ready to be admitted seem to have a philosophy of life or belief system that helped make sense of their new life and situation, something not reflected for those subjected to an involuntary admission. For those who were able to, this sense making involved a letting go of their life before the LTCF and rebuilding or internalizing their life in the LTCF in such a way that they could see a future in the facility in spite of concerns relating to control and autonomy. Two key elements noted by older people for successfully adjusting to life in the LTCF were the establishing of positive relationships and participating in meaningful and productive activities.
Summary of Evidence Credibility – Synthesised Finding 5

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Table 10: Summary of evidence credibility - synthesis finding 5

Summary of Evidence Credibility for all Synthesised Findings

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Table 11: Summary of evidence credibility by synthesis findings
CHAPTER 4. DISCUSSION, LIMITATIONS, CONCLUSIONS & RECOMMENDATIONS

DISCUSSION

In view of the significant history of the quantitative research into the impacts of relocating to a LTCF the fact that there are a relatively small number of articles using a qualitative methodology was surprising. While there are many qualitative studies relating to aged care only a total of 15 published qualitative studies meeting the inclusion criteria where identified between 1983 when Chenitz's article appeared to 2008 when the report on Saunders & Heliker's study was published, a total of 25 years.

Given the significant changes in aged care policy both in Australia and other English-speaking countries over the last 25 years which have had a direct impact on the morbidity characteristics of people entering LTCFs and an increase in the regulations and scrutiny of aged care services it would not be unexpected that the results of the research would vary considerably between the early 1980s and 2008. Similarly there is also a significant spread of geographic settings represented in the studies: USA (7), Canada (2), Hong Kong (2), UK (1), Australia (1) and New Zealand (1) with the studies from the USA being spread across the country representing rural, city, coastal and inland settings. Again it would not be unexpected to see differing research findings due to the variation in policy jurisdictions arising out of the geographic spread. What is remarkable about the systematic review findings is their consistency in key aspects across both time and location. Some key aspects that emerge are outlined below. I have, in the first five points below, selected examples from the studies showing the similarities across different times and countries and included the date and country next to the reference so this can be seen more clearly.

Involuntary moves

This relates to the way the decision for the entry into the LTCF is made. Involuntary admissions are those where the person believes they had no say or no choice in the move. Chenitz(1983 USA) commented that involuntary admissions led to resistance to the relocation by the person which was exhibited in a range of behaviours including withdrawal, crying and expressions of profound hopelessness and helplessness and that the staff or family members described these elders as
"giving up the will to live" or as "just waiting to die"(p95). Iwasiw et al(1996 Canada) report that residents for whom the relocation to a LTCF was made by family, i.e. it was not a voluntary move, not only resisted the move but resented the family members or caregivers who made the decision which has implications for their ongoing relationship. Lee(1999 Hong Kong) reports that the only resident who entered the facility involuntarily felt powerless and hopeless and wished to die. Bland(2005 New Zealand) comments that the circumstances under which a person enters a LTCF can be such that the person is unlikely to feel at home again, anywhere. Marshall & Mackenzie(2008 Australia) comment that participants commonly found it more difficult to accept changes in their living situation and felt 'shoved in' when they were not involved in the relocation decision. It is clear from the review studies that an involuntary relocation to a LTCF has the potential to impact on family relations which are crucial to a successful adjustment to life in a LTCF, and are a significant predictor to poor experiences associated with the relocation and increased difficulties in adjustment, if adjustment is achieved at all. Clearly an involuntary relocation is a demonstrated lack of control over a crucial aspect of one's life, where and how one lives. The impact of lack of control on health and wellbeing is dealt with in a following section. The links between involuntary relocations, difficulties adjusting and adverse health outcomes have been indicated in both the quantitative and qualitative literature for many years as is reported elsewhere in this review. There were no reports in any of the review studies of any LTCF implementing a pro-active approach to identify people who were moving to the facility on an involuntary basis and putting in place interventions or supports to ameliorate potential adverse experiences from the relocation.

**Becoming homeless in a strange world**

The difference between living in your home as opposed to living in an institutional long term care facility is dramatic and this is reflected across the studies. Brooke(1989 USA) reports that participants initially felt a sense of disorganisation characterised by feelings of displacement and abandonment where death wish is common and participants making statements such as "I don't belong here" and "I feel like I am stranded". Lee et al(Hong Kong 2001) reports that participants tried to maintain a lifestyle as close to normal as before admission but none of the residents were able to successful in re-establishing life as 'normal'. Iwasiw et al
(1996 Canadian)\textsuperscript{107} comments that based on their early experiences it seems "residents were living between two worlds, the world they had left and the ones they had entered."(p386). Heliker and Scholler-Jaquish(2006 USA) report that a common theme was participants feeling an "experience of becoming homeless and entering an unfamiliar place"(p37).

In a recent study on the relationship between mobility, place and identity Easthope\textsuperscript{121} comments on the importance of place attachment in shaping our identities. She argues that one's spatial identity is related to place, particularly places of special import such as the home in that there is a sense of belonging to a place. This is evident in a number of studies in the systematic review but none so clearly as in the Marshall & Mackenzie\textsuperscript{113} study where Participant 10 reports, “I have tried very, very hard to settle down and fit in, but I can't because I'm a different person.... I just don't fit in here. It's not my life. It's very hard at my age to alter your personality, and that's what I'm trying to do.” [P129]. Easthope also argues that one's temporal identity finds attachment and expression in the physical environment, both place and possessions, enabling us to concretise memory through association. This aspect also arose in the review. Losing valued possession such as furniture and particularly the home was painful\textsuperscript{42,113} and the value of being able to take some meaningful possessions into the LTCF was well articulated by one study participant: "You've got to take things that are dear to you that you can look at and reflect on ... You can look at them and say 'that's me; that's me, not someone else.'"\textsuperscript{122}(P129) Being prepared for the relocation in advance did make the loss of possessions easier for many people\textsuperscript{107}. People develop strong connection to the places they identify with and will resist change. This sense of place, attachment and identity is, for example, used by Devine-Wright\textsuperscript{123} to explain local community opposition to developments as based on protecting against threats to place-related identity. One striking example of this in the systematic review was Helen's reaction to a request to change rooms: “They wanted me to move upstairs. NO WAY! This is a private room. Upstairs there are all two-bed rooms. I don't want to share my family with others. I like this private place. \textbf{This place is mine.}”\textsuperscript{74}(p40) (underlining added). One gets the sense that the objection is more about the sense of place and how she identifies with it in terms of status (down stairs private room), a place of to be with her family (this is our space) and ownership (this place is mine) than the change in amenity.
While relocations appeared more difficult for people moving involuntarily it is clear that voluntary moves are also difficult. There was no mention in any of the studies of the LTCF acknowledging the traumatic nature of a relocation in terms of the dislocation caused by the loss of home and possessions and no mention was made of any attempts (systematic or by individual staff members) to put in place supportive processes to make the place transition less painful.

**Struggle for identity and retaining control over their life**

Struggle and conflict around maintaining control over one's life was a strong feature in most studies. The centrality of the struggle by people living in LTCF to retain control over their lives was reported by Chenitz (USA 1983)\(^{69}\). Wilson (USA 1997)\(^{114}\) noted that issues relating to control, autonomy and decision making were of concern to nearly all the research participants. Lee (Hong Kong 2001)\(^{120}\) reports that all the participants failed in their attempts to establish a life within the LTCF that reflected pre-admission normality. Iwasiw (Canada 2003)\(^{106}\) reports there was an internal conflict for people as they dealt with the expectation to fit the norms and routines of the LTCF and the conflicting innate desire to continue to be the individuals they were before admission. Bland (New Zealand 2003)\(^{112}\) reporting on a single participant case study commented that for George there was little in his present world (the LTCF) that offered any sense of control. Barredo (USA 2008)\(^{105}\) reports that participants in the research unanimously expressed dissatisfaction with their loss of independence.

The loss of control a person experiences and the deleterious effect on a person's sense of wellbeing has been reported in the literature for decades\(^{124}\). In 1976 Schulz reported on an experiment that looked at the effects on the physical and psychological status of residents in a retirement home by varying the degree of control residents had over visits from college students\(^{124}\). The results demonstrated a consistent and superior impact on indicators of physical and psychological status as well as levels of activity for those residents having the greatest control. In the workplace the link between the low levels of control over the work a person does and disease have also been recognised for a number of years as attested to by the seminal publications on the Whitehall Study lead by Sir Michael Marmot\(^{125}\). Similarly in a review on happiness and human potential Ryan and Deci argue for the importance of autonomy for well-being\(^{126}\). These three examples reflect the general consensus in a significant body of research of a relationship between control and
autonomy and physical and psychological wellbeing. Yet despite the research awareness of this relationship being known for over 40 years there was no mention in any of the review articles of LTCFs acknowledging the importance of this aspect of life on the health and wellbeing of people living in the facilities or making any material proactive effort to enable people to have a meaningful sense of control. This is evident by the consistent and almost universal reports in the studies over the loss of control and independence by study participants.

*Experiences and feelings in relation to the entry into a LTCF are complex, unique and ongoing*

When a person moves into a LTCF it is not a one-time discrete event but rather a highly personalised experience that can take months to complete or, as in some cases, an experience that is never resolved. Chenitz (USA 1983) reported that elders in her study repeatedly discuss the ongoing nature of the adjustment required when moving into an LTCF. Iwasiw (Canada 1996) observed that the number, range and complexity of participants' emotional experiences in relation to moving into a LTCF were surprising. Wilson (USA 1997) commented that the transition to life in an LTCF occurs over time and individual responses vary. Lee et al (1999 Hong Kong) noted that the range of emotional reactions associated with the admission as described by the participants were similar to those reported in other studies and Lee (2001 Hong Kong) reports of varying responses by individuals. Marshall & Mackenzie (Australia 2008) concluded that the way people adjusted to living in a hostel was both an individual and complex process with little uniformity in the experience of the participants.

While it is often a decline in physical or cognitive function that leads to relocation to a LTCF it is the psychological/emotional aspects of the move that seems to have the greatest impact on a person's sense of wellbeing following the move. As reported these impacts are unique, complex and ongoing and as such the nature of the experiences are not such that lend themselves to standardised institutional responses. The nature of the issues would indicate that individualized supports and interventions are required by appropriately qualified staff. There was no mention in any of the review articles about any specific initiative implemented by a LTCF to address the individual psychological or emotional needs of people moving into the facilities. Nor is there any mention of the availability of any appropriately qualified and trained staff such as social workers.
It is a struggle undertaken by the older person

It should be noted that nearly all of the research studies commented on participants who had made a 'successful' transition to an LTCF. Typically these were participants for whom the move into the LTCF was voluntary, where there had been a prior period of reflection and decision-making in terms of the needs and benefits of moving into the LTCF and where people were able to establish new relationships and meaningful activities, while at the same time as retaining some key relationships from before the admission. The sense one gains, however, is that the 'successful' adjustment is a product of the participant’s particular approach to the move rather than by any insightful or organised approach by the LTCF. The emphasis in the reports is on the 'resident' accepting and adjusting, on learning the ropes, finding their way in a strange new world, of navigating new relationships, of finding meaning and purpose of dealing with the emotional and psychological experiences of the relocation. These are difficult challenges for a person decades younger, fitter, healthier and often with reasonable family and social supports at hand. Throughout the studies there was no mention of any recognition by the LTCFs of the immensity of the change that older people entering a LTCF face. It is perhaps not surprising that we find that the depression rates among older people in LTCF in countries like Australia are high\textsuperscript{127, 128} albeit what is disappointing is that a significant percentage of these cases may not be diagnosed or treated\textsuperscript{128}.

Time to adjust

Two grounded theory studies took the approach of identifying various stages in the adjustment process. Brooke\textsuperscript{42} noted four phases; disorganisation, reorganisation, relationship building and stabilization. Most of the residents had reached the stabilization stage within 3 to 6 months with all but 3 of the 42 residents progressing through the stages in eight months. Lee, Woo & Mackenzie\textsuperscript{117} also identified four stages; orienting, normalising, rationalising and stabilising. The authors noted that at around 5-6 months after admission most residents began to enter the final stage. In a phenomenological study Saunders & Heliker\textsuperscript{108} noted that a number of participants had still not adjusted to life in an LTCF in a positive way. Reaching the final stage of adjustment did not necessarily indicate a positive embracing of the new living arrangements and a number of authors spoke of participants resigning themselves to life in the LTCF\textsuperscript{67, 111, 113, 129}. Nor is the time of the difficult adjustment process insignificant with the average stay in an Australia LTCF 3.03 years for women and
2.11 years for men\(^5\).

Given that older people are moving to a LTCF with relatively little time remaining in their lives, many will spend a significant part of that time struggling with the issues of re-adjusting to a LTCF and for many there will be, at best, resigned acceptance. One wonders if this could be significantly changed if the emphasis on clinical and bodily function (activities of daily living) support, which based on the absence of complaint in the review studies are being provided at a satisfactory level, were complimented by a stronger focus on each person's sense of wellbeing. This may make the final years of many more people relocated to LTCFs a more positive and meaningful experience.

**Relationship with staff - are staff at a loss to respond in a meaningful way?**

Intuitively one would have expected the supportive nature of the resident-staff relationship to have a significant presence in the experiences of older people as they adjust to the LTCF. While there are, no doubt, many positive and supportive relationships with staff this did not feature in the research studies. The picture one gets, especially during the initial period following admission, is of a distant uncertain relationship. Lee\(^{120}\) reported that a distant superficial relationship was preferred due to the uncertainty over what the staff resident relationship should be. Iwasiw\(^{106}\) commented that few staff members were considered friends of the participants and Saunders and Heliker\(^{74}\) observed that even after three months residents rarely knew the names of the staff. In 1983 Chenitz\(^{69}\) noted in relation to some residents whose resistance to being in the LTCF was expressed aggressively:

"Since none of the interventions available to staff resolve the elder's conflict, consequences for a forceful resistor are negative: transfer to a more restrictive facility, sedation and restraint, permanent confusion, or death. In these cases, everyone is caught in a downward spiral. No one is satisfied with the results and everyone feels impotent to change the situation"(p96).

While one would hope that interventions have improved since 1983 this quote is the only one from all the studies that reflects the difficulties faced by staff and the sense of impotence in being unable to address the situation faced by many residents. Many staff would be seeing and encountering firsthand the difficulties faced by people moving into a LTCF and given the extent of dissatisfaction experienced by the older people it would be difficult to image that the staff were unaware of this. Is
it possible then that the way LTCFs are structured and the roles that staff are required to carry out do not equip or enable staff to adequately respond to the real, imminent and pressing needs of residents as regards their quality of life? On the one hand aware of the quality of life issues on the other unable to adequately respond? Does this create a sense of impotence as noted by Chenitz and if so does it contribute to the nature of the staff - resident relationships?

The question arises that if the LTCFs had staff appropriately trained to respond to the emotional and psychological needs of residents would this lead to more meaningful and supportive relationships between key staff members and the older adults living in the facilities? Would this lead to improved outcomes for both older people and staff?

**Reflecting back on quantitative studies**

Having completed the systematic review of the qualitative literature on relocation it is worth reflecting back on some of the findings from quantitative studies considered in the Background section of Chapter 1. One of the lines of quantitative research was the identification of factors associated with relocation that are responsible for the adverse effects noted in some studies. Studies report that the following factors influence the outcome from relocation; involuntary rather than voluntary relocation\(^{55-57}\), the degree of difference between the environment of the original location to the final destination \(^{24, 58-61}\), the degree of participation and choice by the person making the move\(^{29, 56, 62}\); and the amount of support and preparation involved in the move process\(^{56, 60, 63, 64}\). These factors have a strong resonance with the findings from this thesis.

It will also be recalled that many of these morbidity studies reported a variety of negative consequences associated with relocation, including depression, increased sense of loneliness and alienation, decrease in functional competence, cognitive decline, decline in general condition and even more extreme morbidity and mortality outcomes, such as falls, injuries, behavioural problems or premature death\(^{30-37}\). Again not only is there a resonance between a number of these findings and the results of this thesis but given the previous discussion on the links between autonomy, control and independence and physical health and wellbeing the other findings have a ring of believability about them. While it is acknowledged that there are quantitative (statistical) studies reflecting benefits\(^{35, 38-41}\) from relocation
even these are not reporting 100% positive outcomes from relocation, so the question lingers, what of the participants in these studies for whom the outcomes were adverse? What level of adverse outcomes is acceptable? With over 50,000 older people permanently entering residential aged care each year in Australia, if only 15% experienced the types of adverse outcomes represented in these findings that would be 7,500 additional older people a year spending the last years of their life struggling with significant emotional and psychological challenges after relocating to a LTCF. The numbers may be significantly higher. Across all economically developed countries using the LTCF model the numbers would be many times that for Australia.

The findings from this systematic review combined with those of previous quantitative studies strongly suggest that the current model of residential care is not working for a significant number of older people.

The studies from Hong Kong.

The studies from Hong Kong included participants who were Chinese speaking elders from a Chinese cultural background. As reported above there were a number of similarities between the experiences of older Chinese participants and those from the other studies. Lee does comment on some specific aspects unique to the Hong Kong experience noted during the studies, some of these are as follows:

- The rules and regulations of the LTCF were valued as contributing to the harmony and balance of the community which was regarded as more important than individual autonomy.

- The issues of shared bathrooms and lack of private spaces were not regarded as important.

- The relationships between residents is often tenuous and Chinese elders experience difficulties in forming relationships with other residents and are thus unable to use other residents as a source of support inside the LTCF.

- There is a sense of face-saving and stoicism emanating from the culture that is exhibited by Chinese elders in LTCFs which may mask difficulties experienced by participants in adjusting to the LTCF.

Notwithstanding these comments the reports by Lee indicated a consistency of
issues for residents in the Hong Kong facilities as can be seen in the preceding sections. The struggle for identity, control and meaning seem to be universal experiences based on reports from this review, with the struggle made more complex by cultural aspects that change the emphasis of particular issues.

**Death and demise**

In his seminal book Being and Time\textsuperscript{130} Heidegger differentiates between the demise of the body and death of Dasein (loosely translated as our being or existence). Blattner\textsuperscript{131} explains that dying is the possibility of no longer being able to be. It is a phenomenon to be understood existentially and is a condition in which we may be alive but we cannot exist. This comes from an understanding that existing is the moving forward in life in response to how we identify ourselves, how our understanding of our self gives meaning to what we do. But it is more than that, identity only makes sense in our world, a world of meaning, a world that is intelligible to us. Our world is an integral part of who we are because it is our world that gives us our identity. When we lose the world we know, there is no longer the structures that gives us meaning, no longer a place in which we can project forward in the future, no longer a place where we can anchor the identity that is us. Following this loss in our world, or collapse of our world, we may be alive but struggling to exist. The challenge is to build a new world in which to re-create our identity, a new world in which to find meaning and project ourselves into the future. All this has a familiarity in the descriptions of moving into a LTCF that have been presented as part of this review. For many people the move to a LTCF is a world collapse and the challenges of re-creating a new world are immense, for others the move is a partial breakdown in their world that needs to be re-ordered around those parts that remain familiar, still a challenging task. The inability to re-create the breakdown in the world results in an existence in which there is no future, the individual is alive yet dead.

The move to a LTCF inflicts significant damage on the being of many people, on Dasein. This can be seen from many of findings reported as part of this study. There is much to be gained in investigating the phenomena of world collapse in relation to the move to a new world, to the LTCF. Heidegger's theory could inform such research.
Summary

In summary the systematic review has provided a challenging description of the experiences for many people of relocation to a LTCF. What is saddening is that the nature of this painful transition process has been consistently reported in the qualitative literature for over 25 years across six countries and yet there is no substantive evidence of any change in the way LTCFs respond to this challenge. Until there is change many older adults are going to spend a considerable portion of their remaining years dealing with the challenges of relocation to a LTCF, some will adjust and experience a new sense of meaning in their lives, others will accept that the new life is as good as it gets, and many will fail to find new meaning at all. If these issues are well reported in the literature then why has there been no significant change? Perhaps this is the single most important question arising out of this review and an area for further research.
LIMITATIONS OF THE REVIEW

There are a number of limitations in relation to the systematic review. Firstly the meta-aggregation methodology, as a form of qualitative research synthesis, has received little attention in the research literature. The main focus has been on meta-synthesis which has its origins in the work of Noblit and Hare\textsuperscript{132}. The JBI meta-aggregation approach was developed based on the consensus of a number of senior researchers\textsuperscript{81} and since then there have been few critical reviews or significant theoretical papers debating the methodology. However it is noted that many of the methods used in meta-aggregation are common to those of meta-synthesis and quantitative systematic reviews and those methods have been widely debated.

Secondly the discovery of qualitative research studies is still problematic\textsuperscript{102} due to indexing issues in recognised research databases, the publication of qualitative research in theses and books rather than journals\textsuperscript{133} and that the methods of identifying relevant studies for a meta-synthesis has not been fully developed in the literature\textsuperscript{134}. Consequently the main issue is one of transparency in disclosing the methods used in the search and the search results\textsuperscript{134} which is the approach taken by JBI\textsuperscript{102} and adopted in this thesis.

Thirdly the review only searched for English language papers and therefore has not identified possible evidence published in other languages.

Fourthly the systematic review was carried out with only the results published in journal articles and access was not obtained or sought to the original research data. The quality of the meta-aggregation has a high dependency on the quality of the included studies and so any superficial or other inappropriate analysis of the primary data may impact on the veracity of the review findings. This is a recognised aspect of synthesis and is addressed by the JBI methodology in a robust appraisal process which was used in this thesis.

Fifthly the review identifies qualitative evidence relating to the experience of moving onto a LTCF. There are a number of issues that may contribute to the negative experiences reported including age related morbidities and frailties which may be contributing to these experiences apart from the move. In other words the review is not describing causal relationships.

Finally the systematic review is at a given point in time. The review does not take into account any published material since the search was undertaken.
CONCLUSIONS

The review identified 14 studies (15 articles) and generated five synthesized findings relating to the experience of older adults moving into a long-term care facility. Even though the review studies covered a period of 25 years and 6 different countries there was a remarkable consistency in the experiences reported by the various research participants.

Prior quantitative research had been inconclusive in articulating a consistent picture of the benefits or detriments to the health and well-being of older adults from a move to a LTCF, however what cannot be ignored are those quantitative studies that persistently report adverse outcomes for older adults. This systematic review of the evidence from qualitative research provides a poignant picture of the struggles and challenges facing many older adults as they enter a LTCF. Each person faces their own unique struggle as they move from the known world of their home to an alien world of the aged care facility, trying to retain a sense of their own personhood and create a sense of place meaningful to them as they are pressured to conform to the will of the institution.

The staffing of LTCFs is traditionally based around attending to the clinical and bodily frailties of older adults and so the professional staff are typically clinically trained nurses supported by ancillary nursing staff and personal carers. It is questionable whether the professional training provides the staff with the competencies necessary to address the profound psychosocial and emotional needs of newly admitted older adults. It is also questionable whether there are sufficient resources given to provide opportunities and support for people to engage in individualised meaningful occupation reflective of who they are as individuals. One of the hopes of this review is to raise the awareness of policymakers, administrators and the nursing profession of the significant gaps that exist in this area.

Many admissions to LTCFs would be classified as involuntary. A typical pattern is a slow decline in frailty followed by an adverse incident such as a fall leading to hospitalisation and admission to a LTCF. This relocation process is often driven by well meaning concerned family members with the best intentions, and yet the process leads to significant barriers to a successful transition to a LTCF. The second major hope of this review is to raise the awareness of policymakers and administrators to resource a more humane and supportive transition and to raise the
awareness of families so they can balance their legitimate concern for the older persons physical well-being with the, perhaps even more important aspect, the older person's psychological and emotional well-being.

Older adults moving into LTCFs are amongst the most vulnerable people in our community. Despite a research history going back more than 60 years that has continually raised concern about the transition into care facilities and the potential negative impact on a person's sense of well-being, and ultimately their physical health, there is no indication that policymakers, aged care administrators or the nursing profession have taken this issue seriously. The third hope is that the impact of institutionalisation and the transition processes associated with institutionalisation will get the same attention as was provided to people with disabilities and their struggle against institutionalisation in the latter part of the 20th century.
IMPLICATIONS AND RECOMMENDATIONS

Implications and Recommendations for Policy Makers

The provision of aged care services in economically developed countries is subject to significant government involvement in terms of policy, regulation and funding. It is important therefore that governments are provided with the best available evidence concerning the provision of aged care services and any identified gaps. This systematic review has identified a number of gaps in the provision of aged care services based on the psychological and emotional needs of older people moving into the LTCFs.

It is recommended that policy makers review the following recommendations with a view to minimising harm that may result from a move to a LTCF:

To reduce the harm resulting from involuntary admissions:

- Initiating an awareness program for family doctors, hospitals and LTCFs on the potential harm from involuntary admissions and providing information as to what would constitute a sensitive and supportive decision-making processes for families; and

- Investigating the need for service funding to support and facilitate appropriate decision-making processes for older people recently admitted to hospital and at risk of LTCF institutionalisation.

To reduce the harm arising from the sense of homelessness, alienation and depersonalization when moving to a LTCF:

- Identifying and implementing strategies to impact on the decision making processes and transition process to a LTCF so as to minimise the harm arising from the sense of homelessness, alienation, and depersonalization;

- Identifying strategies that LTCFs can implement to reduce the sense of homelessness and alienation and actively promote those strategies to LTCF administrators and professional staff;

- Providing funding for area based social workers to assist LTCFs identify and address the psychological and emotional needs of older adults as they move into
the facility; and

- Identifying the unique professional knowledge and skills required by nursing staff within LTCFs and providing funding to tertiary institutions to incorporate that knowledge into professional nursing education.

**Implications and Recommendations for Practice**

LTCF administrators and the nursing profession have a significant influence on the allocation of staffing resources, staffing mix and service delivery models within facilities. Given the desire to ensure the best possible outcomes for older people not only clinically but for their emotional and psychological wellbeing and quality of life experience it is important that both administrators and nursing professionals make the decisions on the best available evidence. This systematic review has identified practice and/or service delivery gaps which if addressed may help to reduce the harm arising out of the institutionalisation of older adults.

It is recommended that administrators and nursing professionals review the following recommendations with a view to making appropriate changes to service delivery within LTCFs.

*To reduce the harm resulting from involuntary admissions:*

- At the time of an enquiry or application for admission ensure the older person and/or family are provided with information as to the best possible decision making processes and the possible consequences of involuntary admissions.

*To reduce the harm arising from the sense of homelessness and alienation when moving to a LTCF:*

- Provide education for all staff in relation to the sense of homelessness and alienation experienced by many older people moving into a LTCF; and

- Identify strategies that can be used in relation to each individual person to support them in establishing a sense of place and connection within the LTCF as quickly as possible in a way that is meaningful to them.

*To reduce the harm arising from the sense of depersonalization when moving to an LTCF:*

- Review the decision making process for all aspects of the LTCFs activities that
have a bearing on the life of each older person and develop ways of significantly increasing, in a meaningful way, the involvement and participation of older people in both the decision making and the activities themselves; and

- Ensure sufficient resources are provided to enable people who live in a LTCF to have the opportunity and support to participate in occupations/activities based on activities that are meaningful to them.

**Implications and Recommendations for Research**

The review identified a number of areas that would benefit from further research:

- The nature and effectiveness of pre-planned responses to relocating to a LTCF;

- The awareness and understanding of the staff of LTCFs about the difficult nature of the relocation to a LTCF by older people;

- To what extent, if any, there is a sense of impotence or inadequacy felt by staff regarding their ability to adequately respond to the needs of residents experiencing difficulties with a relocation to a LTCF;

- The nature of the relationship between residents and staff and to what extent this contribute to a resident's sense of wellbeing within the LTCF;

- The awareness by family members and family doctors as to the range of outcomes experienced by older adults moving into a LTCF and the extent to which an awareness of the negative risks may impact on the decision making process;

- The role of the family doctor in relation to involuntary admissions and how the role may be enhanced to reduce the harm resulting from involuntary admissions;

- The development, trialling and evaluation of alternative transition support programs in relation to the decision-making and move associated with relocating to a LTCF;

- Identification of the necessary knowledge and skills required to support the psychosocial and emotional aspects of an older person's life in their transition to and within a LTCF and an evaluation of the capability and capacity of existing LTCF staffing models to provide those requirements;
• An evaluation of the adequacy of the current divisional therapy and/or lifestyle programs within LTCFs in relation to meeting the individual older persons need for meaningful occupation; and

• Phenomenological research into the experience of a permanent relocation to a LTCF focussing on the extent to which this leads to a 'world collapse or breakdown' for those making the relocation, the way people are impacted and the way in which they respond.

The value of meta-aggregation in synthesizing the available evidence from the qualitative research in a particular field is evident from this systematic review, however one of the limitations of the review is the undeveloped literature around meta-aggregation methodology as part of the evidence-based practice movement. This is an area that would also benefit from further research.

Keywords
systematic review; long term care facility; nursing home; relocation; relocation stress; older adults; meta-aggregation; qualitative research; synthesis; evidence based practice
CONFLICT OF INTEREST

There is no conflict of interest to declare in relation to the work contained in this thesis.
APPENDICES

Appendix I: Search Tables

Table 1: Starting search terms

<table>
<thead>
<tr>
<th>Related to population</th>
<th>Related to phenomenon</th>
<th>Related to context</th>
</tr>
</thead>
<tbody>
<tr>
<td>over 65 elderly older adult</td>
<td>relocation transition admission move</td>
<td>nursing home long term care</td>
</tr>
</tbody>
</table>

Table 2: Key Words

<table>
<thead>
<tr>
<th>A POPULATION</th>
<th>B PHENOMENA</th>
<th>C CONTEXT</th>
<th>D EFFECT</th>
<th>E RESEARCH TYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>aged dementia elderly elders geriatric old age older adult older people older persons older women over 65 patients residents senior adults very old</td>
<td>adapted adjusting admission admitted entry environmental change institutionalisation move moving to placement relocated/ing/ion resettlement transfer transition translocation</td>
<td>assisted living care-home congregate from home health care facility home for - incurables home for the aged hostel institution long term care nursing home residential care residential facility residential home skilled nursing facility/ SNF</td>
<td>relocation-syndrome transfer trauma relocation stress admission stress relocation shock transplantation shock</td>
<td>action research cluster sample constructivist constructivism content analysis discourse ethnography ethnological ethno-methodology focus group grounded theory hermeneutic heuristic interpretive interpretive life experience lived experience meaning narrative observational perspectives phenomenological phenomenology purposive sample qualitative semiotics thematic analysis</td>
</tr>
</tbody>
</table>
Table 3: Databases of peer reviewed literature

Academic OneFile
Academic Search Premier
CINAHL
CSA Sociological Abstracts
Current Content Connect Health Source: Nursing/Academic Edition
Periodicals Archive Online
Periodicals Index Online
Psychology and Behavioural Sciences Collection
PsycINFO
PubMed/Medline
Scopus
Social Services Abstracts
Sociological abstracts (Sociofile)
Web of Science

Table 4: Grey Literature & Unpublished Studies

Grey Literature -New York Academy of Medicine
pre-CINAHL
Scirus
EthOS
Networked Digital Library of Theses & Dissertations (NDLTD)
Proquest
Dissertations & Theses Canada Portal
NOTE:
This appendix is included on page 105 of the print copy of the thesis held in the University of Adelaide Library.
Appendix III. QARI Data Extraction Instrument

NOTE:
This appendix is included on page 106 of the print copy of the thesis held in the University of Adelaide Library.
Appendix IV. Results of Data Extraction from QUARI STUDIES INCLUDED IN REVIEW

<table>
<thead>
<tr>
<th>STUDY 1</th>
<th>A descriptive study of losses associated with permanent long-term care placement (2008)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>Barredo, R.D.V.; Dudley, T.J.</td>
</tr>
<tr>
<td>Methods</td>
<td>Face to face interviews were carried out with the participants. Open ended questions were used during the interview which ranged from 1 to 1½hrs. Second interviews with participants were conducted for checking, clarification and elaboration. Interviews continued with successive participants until saturation was reached. Interviews were taped and transcribed verbatim</td>
</tr>
<tr>
<td>Participants</td>
<td>All participants were required to meet the following inclusion criteria: - placement within the past 12 months; - absence of acute disease; and - cognitive ability to respond to and communicate during interview sessions. The five participants (three female and two male) were selected using convenience sampling. Four were widowed and the fifth was married with his wife already residing in the facility. All participants were over 75 years of age. The two men had worked until retirement, one as a coach at high school and the other as a farmer and factory worker. All the women had worked periodical in a retail or office employment. All participants satisfied the inclusion criteria.</td>
</tr>
<tr>
<td>Phenomena</td>
<td>Experiences of loss expressed by older adults moving to long term care.</td>
</tr>
<tr>
<td>Conclusion</td>
<td>There are loses experienced by people as part of specific generation cohorts. There are individual losses (physical or cognitive capacity) experienced by individuals prior to admission to a LTC (antecedent losses) which contribute to the placement decision. This is then followed by losses (independence, relationships, activities) experienced arising out of the placement (consequent losses). The losses experienced by participants prior to admission to long term care were cumulative and associated with the eventual placement to long term care. The losses identified as leading to placement were consistent with current research. Following placement the experience of loss differed significantly between the genders with males expressing a marked sense of meaningful activity. The move to LTC may also interfere with the need to attend to end of life role expectations resulting in the experience of additional loss. The study highlights the need in prolonging function, preserving quality of life, and preventing for as long as possible LTC placement.</td>
</tr>
<tr>
<td>Notes</td>
<td>A well-constructed and thoughtful study that explicates the experience of loss for people moving into long term care. The study could have been made more rigorous by more clarity in the study methodology.</td>
</tr>
</tbody>
</table>

| STUDY 2 | The challenge of feeling 'at home' in residential aged care in New |

| 107 | Page |
## Zealand (2005)

**Researcher**  
Bland, M.

**Methods**  
Data collection included 90 days of participant observation, extensive document examination, and formal interviews with residents and staff. Semi-structured interviews were held with these residents on two or three different occasions, usually in the relative privacy of their own single bedroom.

**Participants**  
Participants of the larger study were residents who were able to provide informed consent to participate in the study. George, the subject of this case study report, was 85 and had been in the nursing home just over six months.

**Phenomena**  
The challenge of feeling at home in residential aged care in New Zealand.

**Conclusion**  
Residents may have to overcome significant challenges if they are ever to feel truly at home in a nursing home environment and because each resident has a unique story and ways of being in the world individualising nursing care is essential if residents are to achieve any degree of comfort in this strange new world [the nursing home] where they will spend the rest of their lives.

**Notes**  
A good study well reported that illustrates the tragic consequences of what happens when nursing care is not adequately followed nor sensitizes to the particular needs of the individual.

## STUDY 3  
Nursing home life: how elders adjust (1989)

**Researcher**  
Brooke, V.

**Methods**  
Over a one year period the researcher was involved in admitting residents, orienting them to the facility, initiating the care plan and providing some care. Observational field notes and verbatim notes were taken. Two to five times per week each resident was asked questions about their experience of living in the facility. Hand written notes were made of the interviews.

**Participants**  
Forty two newly admitted residents (eleven men and thirty one women) aged 65 to 98 years (mean age 84.5 years). The residents were admitted on an indefinite period rather than a limited period associated with the hospice or rehabilitation. There was no exclusion due to physical or cognitive impairment. 65% were moderately to severely cognitively impaired and 70% were dependent in two or more ADLs.

**Phenomena**  
The adjustment of elders relocating to a LTCF.

**Conclusion**  
Four major phases in the process of adjustment to living in a nursing home emerged: disorganization, reorganisation, relationship building and stabilization. Within 8 months 93% of participants passed through all stages with only 3 of the 42 not
doing so. They remained in the disorganized phase.

Notes  This was one of the first qualitative studies of the experience of moving into a LTC facility.

<table>
<thead>
<tr>
<th>STUDY 4</th>
<th>Entry into a nursing home as status passage: a theory to guide nursing practice that can ease adjustment (1983)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>Chenitz, W. C.</td>
</tr>
<tr>
<td>Methods</td>
<td>Participants were interviewed from the time of their admission several times per week for 6 to 9 months. Observations were made of care, medical records reviewed and informal interviews held with family, staff and physicians. Data were stored in notes and on tape.</td>
</tr>
<tr>
<td>Participants</td>
<td>Thirty elders, twenty two women and eight men, aged between 63 and 96 years old (mean age 79). All participants were alert and oriented at time of admission. No ethnic, cultural or socio-economic information provided in relation to residents.</td>
</tr>
<tr>
<td>Phenomena</td>
<td>The experiences of adjustment following relocation to a nursing home.</td>
</tr>
<tr>
<td>Conclusion</td>
<td>The entry into a nursing home engages the elder in a major life change and the nature of the responses of the elder are often related to the conditions leading to the admission. While some degree of stress is expected even for elders who accept their admission, the range of abilities to cope with the change will vary with some elders being overwhelmed by the admission process and being unable to cope will experience a crisis. Understanding the elders' responses and the conditions that produce them is essential for accurate nursing assessment and the theory generated from the study that nursing home admission may precipitate a crisis gain be used to guide nursing inversions.</td>
</tr>
<tr>
<td>Notes</td>
<td>One of the first qualitative studies attempting to generate a theory around the admission of elders to a nursing home. Given the period of the study it is well reported and presents valuable findings.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STUDY 5</th>
<th>Transition of new residents to long-term care: basing practice on residents' perspective (2006)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>Heliker, D.; Scholler-Jaquish, A.</td>
</tr>
<tr>
<td>Methods</td>
<td>Interviews with open ended questions commenced in the first week following admission and periodically thereafter for a 3-month period. Interviews lasted from 15 minutes to 1 hour depending on participants' fatigue and interest. Field and interview journal notes were maintained on all observations during the nursing home visits.</td>
</tr>
<tr>
<td>Participants</td>
<td>A convenience sample of 10 volunteers was selected from newly admitted, cognitively intact residents. No additional information provided.</td>
</tr>
</tbody>
</table>
was provided in relation to gender, age, culture or socio-economic background of participants

<table>
<thead>
<tr>
<th>Phenomena</th>
<th>Experiences of older people relocating to a LTCF.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conclusion</td>
<td>Themes that emerged were becoming homeless, learning the ropes and getting settled, and creating a place. Understanding residents' experience of transition leads to innovative practice changes in anticipation of individuals' needs.</td>
</tr>
<tr>
<td>Notes</td>
<td>The study report indicates it was well designed and carried out. The reporting is thorough, well presented and easy to read.</td>
</tr>
</tbody>
</table>

**STUDY 6**


**Researchers** Iwasiw, C.; Goldenberg, D.; Bol, N.; MacMaster, E.

**Methods** Each resident was interviewed by the same researcher over the duration of the study. Interviews were taped and lasted from 30 - 60 minutes. There were 6 interviews conducted 2 and 6 weeks and 3, 6, 9 and 12 months following admission. Prepared open ended questions were used.

**Participants** Seven residents and three family members agreed to participate but one resident died after one month. Only data relating to the residents was extracted. Of the six residents there were five males and one female. Aged from 75 to 88 years. One was married, one divorced, three widowed and one never married. Two had no family nearby. Five men were WWII veterans.

**Phenomena** The experiences of older adults following a relocation to a LTCF.

**Conclusion** That by listening to residents' and family members' nurses can use the information to improve life for residents and dignify them as individuals.

**Notes** A good study well reported.

**STUDY 7**

Residents' perspectives of their first 2 weeks in a long-term care facility (1996)

**Researchers** Iwasiw, C.; Goldenberg, D.; MacMaster, E.; McCutcheon, S.; Bol, N.

**Methods** Interviews were conducted with prepared open ended questions. The interviews were carried out concurrently by the five investigators. The interviews were taped and lasted from 30 to 60 minutes in length.

**Participants** A purposive sample was selected which comprised twelve participants (10 women and 2 men) aged from 67-96 years of age. One was married and 11 were widowed or widowers and all but one had children. The inclusion criteria consisted of; at least two
weeks in facility, admission on a permanent basis directly from home, required to speak and understand English, free of speech and hearing problems that would impede understanding and no overt signs of psychopathology. No other information provided.

<table>
<thead>
<tr>
<th>Phenomena</th>
<th>The experiences of older people immediately following their relocation to a LTCF.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conclusion</td>
<td>The study emphasised that prior to admission to a long term care facility the need for individuals to believe that they are ready to leave their homes and that they should be involved in the decision making and that voluntary relocation does facilitate acceptance, adjustment and greater life satisfaction.</td>
</tr>
<tr>
<td>Notes</td>
<td>A good study well reported that illustrates the need for people to be actively involved in the decisions surrounding their move to a care facility.</td>
</tr>
</tbody>
</table>

**STUDY 8**

**Transition to residential care: experiences of elderly Chinese people in Hong Kong (1999)**

**Researcher**

Lee, D.T.F.

**Methods**

Taped informal interviews were conducted with residents 1 week after admission using open ended questions. The interviews took place in a private meeting room.

**Participants**

Ten voluntary participants selected with no hearing or speech problems using purposive sampling. There were 6 females and 4 males aged from 68-88 (mean age 78). All were voluntary admission except 1. 4 still married, 3 widowed, 3 never married. 4 rated health as good, 2 had diabetes and hypertension, 1 suffered from heart failure, 2 had strokes, 1 suffered from obstructive airways disease.

**Phenomena**

The experiences of older adults following their relocation to a LTCF.

**Conclusion**

A number of issues, such as living with rules and regulation and lack of privacy and autonomy suggested in the literature as barriers to adjusting to living in long term care were not regarded as important by Chinese elders while there were restrictions in developing new relationships with staff and residents. This was attributed to the Chinese values of balance, harmony and collectivism which made it easier to accept communal living while at the same time making new relationship building difficult.

**Notes**

The study report indicates that it was reasonable well designed and carried out. However the conclusions are based on interviews after only 1 week of residency and the Iwasie et al (2003) study did show similar positive comments after 1 week which changed significantly after 3-5 months.

**STUDY 9**

**Perceptions of Hong Kong Chinese elders on adjustment to**
<table>
<thead>
<tr>
<th>Researchers</th>
<th>Lee, D.T.F.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methods</td>
<td>Taped informal interviews were conducted with residents 1 week after admission and then monthly until no new information could be discovered. A total of 98 interviews were held. Open ended questions and probing questions were used. The interviews took place in a private meeting room.</td>
</tr>
<tr>
<td>Participants</td>
<td>18 newly admitted elders (9 men and 9 women) who could understand and speak Cantonese and were permanent residents of the home. The ages ranged from 70 to 86 years of age (mean age 79). 4 were married, 3 single and the rest widowed. 15 admissions were voluntary and 3 involuntary.</td>
</tr>
<tr>
<td>Phenomena</td>
<td>The experiences of older adults following their relocation to an LTCF</td>
</tr>
<tr>
<td>Conclusion</td>
<td>Newly admitted elders adjusted through the four stages of orienting, normalizing, rationalizing, and stabilizing as they struggled to regain normality with a life that was as close to that lived before admission as possible. For Chinese elders a number of experiences suggested in the literature as barriers to adjustment, such as living with rules and regulations and the communal nature of nursing home life were not regarded as important while establishing relations with other residents was a particular challenge for them.</td>
</tr>
<tr>
<td>Notes</td>
<td>This paper reports on the same study as the 2003 paper by Lee et al. The findings have been combined under the Lee et al (2003) paper,</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STUDY 10</th>
<th>The cultural context of adjusting to nursing home life: Chinese elders' perspectives (2002)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>Lee, D.T.F.; Woo, J.; Mackenzie, A.E.</td>
</tr>
<tr>
<td>Methods</td>
<td>Taped informal interviews were conducted with residents 1 week after admission and then monthly until no new information could be discovered. A total of 98 interviews were held. Open ended questions and probing questions were used. The interviews took place in a private meeting room.</td>
</tr>
<tr>
<td>Participants</td>
<td>18 newly admitted elders (9 men and 9 women) who could understand and speak Cantonese and were permanent residents of the home. The ages ranged from 70 to 86 years of age (mean age 79). 4 were married, 3 single and the rest widowed. 15 admissions were voluntary and 3 involuntary.</td>
</tr>
<tr>
<td>Phenomena</td>
<td>The experiences of older adults following relocation to a LTCF</td>
</tr>
<tr>
<td>Conclusion</td>
<td>Newly admitted elders adjusted through the four stages of orienting, normalizing, rationalizing, and stabilizing as they</td>
</tr>
</tbody>
</table>
struggled to regain normality with a life that was as close to that lived before admission as possible. For Chinese elders a number of experiences suggested in the literature as barriers to adjustment, such as living with rules and regulations and the communal nature of nursing home life were not regarded as important while establishing relations with other residents was a particular challenge for them.

Notes  The study report indicates it was well designed and carried out. The results reporting could have been strengthened by increasing the amount of supporting evidence for findings

<table>
<thead>
<tr>
<th>STUDY 11</th>
<th>Adjustment to residential care: the experience of newly admitted residents to hostel accommodation in Australia (2008)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>Marshall, E.; Mackenzie, L.</td>
</tr>
<tr>
<td>Methods</td>
<td>In-depth semi-structured interviews.</td>
</tr>
<tr>
<td>Participants</td>
<td>Inclusion criteria required participants to have been admitted to the facility within last six months, be able to coherently describe their experiences, be able to consent to participating. All residents meeting inclusion criteria invited to participate. 80% accepted invitation. There were 11 participants (8 female and 3 male) with ages ranging from 72- to 92 (mean 80).</td>
</tr>
<tr>
<td>Phenomena</td>
<td>Experiences of older adults following relocation to a hostel.</td>
</tr>
<tr>
<td>Conclusion</td>
<td>The study findings indicate that adjustment to a hostel is an individual and complex process with little uniformity in the experiences of the participants and that accounts of successful adjustment provided by study participants demonstrate the importance of participating in meaningful occupations.</td>
</tr>
<tr>
<td>Notes</td>
<td>The study report indicates that the study was well designed, carried out and reported.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STUDY 12</th>
<th>The importance of place for older people moving into care homes (1998)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>Reed, J.; Payton, V.R.; Bond, S.</td>
</tr>
<tr>
<td>Methods</td>
<td>Interviews</td>
</tr>
<tr>
<td>Participants</td>
<td>People on waiting list for admission able to understand study and converse without serious difficulty. 46 participants recruited, including 5 who gave retrospective interviews approx 1 year after moving, 5 participants withdrew and 1 died. All the participants moved to a facility within 10 miles of their home. No additional information available. Staff were part of study but these have been excluded for the purposes of this systematic review.</td>
</tr>
<tr>
<td>Phenomena</td>
<td>The experiences and views of older people moving into care homes</td>
</tr>
</tbody>
</table>
(nursing and residential).

**Conclusion**
Geographical issues may not be evident to those who have cars and can travel easily and quickly between places, but to neglect this aspect of moving may well result in older people losing contact with friends, neighbours, and social groups as the locality where people have lived is, it seems to be part of the way that some older people describe themselves they ‘belong’ to distinct places.

**Notes**
A good study report with an interesting use of life histories.

<table>
<thead>
<tr>
<th>STUDY 13</th>
<th>Lessons Learned From 5 Women as They Transition Into Assisted Living (2008)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Researchers</strong></td>
<td>Saunders, J. C.; Heliker, D.</td>
</tr>
<tr>
<td><strong>Methods</strong></td>
<td>Interviews using open ended questions. There were two interviews in the first month and then one each month for the next 6 months. The interviews were conducted in a place of the participants choosing, usually their room</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>To meet the inclusion criteria participants needed to be English speaking and able to communicate experiences and have a Min-Mental score greater than 25. All individuals admitted to the ALF during 2003-4 were invited to participate. The five participants were Caucasian and aged between 63 and 91 years (mean age 80)</td>
</tr>
<tr>
<td><strong>Phenomena</strong></td>
<td>Experiences of older adults following relocation to an assisted living facility.</td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td>Admission to a long-term care facility is a time of disorganization and adaptation for new residents who experience a transition breakdown beginning with a sense of homelessness as they learn the rules of institutional living however with the passage of time, residents may be able to create a place of their own often using story sharing as an important way to help new residents integrate into the unfamiliar long-term care facility</td>
</tr>
<tr>
<td><strong>Notes</strong></td>
<td>A good study well reported.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STUDY 14</th>
<th>Moving to an assisted living facility: exploring the transitional experience of elderly individuals (2004)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Researchers</strong></td>
<td>Tracy, J. P.; DeYoung, S.</td>
</tr>
<tr>
<td><strong>Methods</strong></td>
<td>Group interviews were with open-ended questions and free discussion from the individuals about their experiences of making the transition from a private home to an assisted living facility.</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>Participants were selected based on their ability to recall and express feelings concerning their move into the facility. In addition, participants were required to have lived in the facilities between 6 weeks and 14 months, speak English, and be able to</td>
</tr>
</tbody>
</table>
provide written and verbal consent.. There were 28 participants (19 female and 9 male) age from 68-93. Of the participants 9 were married, 15 widowed, 1 divorced and 3 were single.

<table>
<thead>
<tr>
<th>Phenomena</th>
<th>The experiences of older adults following relocation to an assisted living facility.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conclusion</td>
<td>The general structural description of the transitional experience emerged from situated descriptions and reflected five recurring themes: Self-motivated move versus familial encouragement, ties to the past versus, starting anew, independence versus dependence, affection versus disdain and adjustment versus maladjustment. Themes were common across participants and reflected the essence of the phenomenon of transitional experience from a private residence to an assisted living facility.</td>
</tr>
<tr>
<td>Notes</td>
<td>This study used group interviews to explore the experiences of residents. The study aimed to capture the transition experience which appears to change over time through just one group interview per facility. This does not negate the findings or veracity of resident illustrations provided.</td>
</tr>
</tbody>
</table>

**STUDY 15**
The transition to nursing home life: a comparison of planned and unplanned admissions (1997)

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Wilson, S.A.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methods</td>
<td>Data collected 24 hours after admission and every day for 2 weeks, and 1 month after post admission using in-depth semi-structured interviews and observations. The recorded interviews lasted 45-60 minutes and took place in the participant's room or other private area.</td>
</tr>
<tr>
<td>Participants</td>
<td>Eligible participants were required to be adults 65 and older, be able to understand and speak English, pass a short portable mental status questionnaire with 2 or less errors and the admission to a nursing home was expected to be permanent. There were 15 participants (11 females and 4 males) aged from 76 to 97. 3 people approached to participate in the study declined.</td>
</tr>
<tr>
<td>Phenomena</td>
<td>The experiences of older adults following planned and unplanned relocation to a nursing home.</td>
</tr>
<tr>
<td>Conclusion</td>
<td>The transition to nursing home life is a process that occurs over time and varies from individual to individual and generally occurs in three phases: overwhelmed, adjustment and initial acceptance phase. Factors such as voluntary versus involuntary admission, personality, age, autonomy, privacy, possessions and private rooms all affected the transition process in different ways.</td>
</tr>
<tr>
<td>Notes</td>
<td>A good study well reported.</td>
</tr>
</tbody>
</table>

**Table 5: Description of studies**
STUDIES EXCLUDED FROM REVIEW

<table>
<thead>
<tr>
<th>STUDY 16</th>
<th>Understanding the dynamics of life in care homes for older people: implications for de-institutionalizing practice (1997)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Researchers:</strong></td>
<td>Reed, J.; Payton, V.R.,</td>
</tr>
<tr>
<td><strong>Methods:</strong></td>
<td>Interviews</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>People on waiting list for admission able to understand study and converse without serious difficulty. 46 participants recruited, including 5 who gave retrospective interviews approx. 1 year after moving, 5 participants withdrew and 1 died. No additional information available. Staff were part of study but findings associated with staff can be isolated.</td>
</tr>
<tr>
<td><strong>Phenomena</strong></td>
<td>Life in a LTCF one year after relocating.</td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td>We contend that attempts to develop practice in care homes to overcome the effects of institutionalization, frequently promoted through the concept of individualized care within the context of the carer-resident relationship, could benefit from a parallel recognition of the importance of resident groups in enhancing the experience of life in care homes that is just as individuals have needs, so too do the home communities of which these people are members.</td>
</tr>
<tr>
<td><strong>Notes</strong></td>
<td>Note: paper excluded on methodological grounds; criteria 8 of appraisal criteria not met</td>
</tr>
</tbody>
</table>
Appendix V. List of Included and Exclude Studies

Studies included in review following appraisal


*--These two articles report on the same study and as such were treated as one study for the purpose of extracting findings.

Studies excluded following appraisal


Excluded due to insufficient representation by participants.
REFERENCES:

17. Aldrich C, Mendkoff E. Relocation of the aged and disabled: A mortality


36. Scocco P, Rapattoni M, Fantoni G. Nursing home institutionalization: A


52. Castle NG, Sonon KE. The search and selection of assisted living facilities by elders and family. Medical Care 2007; 45(8):729-38.


54. Davis RE, Thorson JA, Copenhaver JH. Effects of a forced institutional relocation on the mortality and morbidity of nursing home residents.


81. Pearson A. Balancing the evidence: Incorporating the synthesis of qualitative data into systematic reviews. JBI Reports 2004; 2(2):45-64.


85. Downe S. Metasynthesis: a guide to knitting smoke. Evidence Based


121. Easthope H. Fixed identities in a mobile world? the relationship between


129. Leith KH. 'Home is where the heart is...or is it?': A phenomenological exploration of the meaning of home for older women in congregate housing. Journal of Aging Studies 2006; 20(4):317-33.


