SYSTEMATIC REVIEW PROTOCOL

"The experiences of older adults moving into residential long term care. A systematic review of qualitative studies."
TITLE PAGE

Review Topic

"The experiences of older adults from moving into residential long term care. A systematic review of qualitative studies."

Review Team

Primary Reviewer:
Stephen Richards, Candidate (Masters of Clinical Science) The Joanna Briggs Institute, University of Adelaide
Stephen.J.Richards@Adelaide.edu.au

Associate Reviewer:
Dr. Christina Hagger, Research Fellow The Joanna Briggs Institute Adelaide University

Commencement date: August 2010
Expected completion date: May 2011
REVIEW PURPOSE & OBJECTIVES

Purpose

The overall purpose of the review is 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 residential long term care. From this evidence it is hoped to gain a better understanding of this relocation experience from the older person's perspective.

A better understanding of the relocation experience will be able to inform care service practice in meeting the needs of older people as they as they move into a long term care facility. A better understanding will also inform policy in determining the nature of the services required by older people requiring ongoing personal and clinical support.

Objective & Review Questions

The objective of this review is to establish the meaning of moving into long term residential care and the experiences associated with the move.

The specific question to be addressed is:

What is it like for older people when they make a permanent move from home into residential aged care?
BACKGROUND

The world is ageing at an increasing and unprecedented rate than hitherto 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.\textsuperscript{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 ageing of the Australian population is not a new phenomena \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 1907\% to 48, 483 home care palaces 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 residential aged care permanently and another 51,293 entered for temporary respite care. For permanent admission in 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 aged 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 an half decades on.

Lieberman articulates the reason for this ongoing interest in a review in 1969\textsuperscript{14} when he comments the research was one of "humanitarian interest" in relation to the impact on the "psychological well-being and physical integrity" of older people arising from institutionalisation. This concern arose out the results of the early studies which suggest that mortality rates post transfer were higher than expected for older people.\textsuperscript{6,15-19} Camargo and Preston\textsuperscript{6} report mortality rates 2½ to 11½ times the rate in the general population for people aged over 65 during the year following admission to “mental hospitals” while Aldrich and Mendkof \textsuperscript{17} report that the “social and psychologic effect” from relocation can be “lethal”.\textsuperscript{[p192]} The concern is also reflected in the differing terminology used in relation to the relocation effect. For example the terms relocation stress, relocation syndrome, relocation trauma, translocation syndrome, translocation trauma, and transplantation shock are used throughout the history of the literature.\textsuperscript{20-22}
While there are earlier studies that note increased mortality rates there are also studies that report no mortality effect or even a positive effect from relocation.\textsuperscript{23-26} Drawing conclusions from these apparently conflicting research findings was difficult due to the differing measures used\textsuperscript{23} and a number of methodological problems such as small population sizes, the lack of comparability in populations, and differing research approaches.\textsuperscript{27-29}

The initial mortality research was followed by research on the broader morbidity effects arising from the relocation of older people and many studies report 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} A number of the research studies reporting negative mortality or morbidity effects indicate that a significant portion of the effect arises in the initial period following relocation and usually in the first three months.\textsuperscript{17,23,38} As with the mortality studies, the negative morbidity effects of relocation are not consistent with other studies which report positive outcomes such as improved emotional well-being, enhanced environmental awareness, increased activity participation and greater social engagement.\textsuperscript{35,39-42}

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, something that can be seen in both the comments and conflicts that have arisen in the literature. One difficulty is noted in the early 1960s when Aldrich and Mendkoff comment that because it was generally declining health that precipitated the relocation to an institution it is difficult to determine if the reported increase in morbidity or mortality rates is associated with the move \textit{per se}, due to health factors or the separation from family. Blenkner reflects this difficulty when she notes that many of the early studies that report increased mortality rates are based on admissions of elderly people to “mental hospitals” and involve people with possibly critical pre-existing conditions.

Questions have also been raised about study design. In the 1970s Lieberman challenges the research community over the disparity of research approaches, methodological problems and a "lack of elegance" in random design and quasi-experimental methods. Sentiments that are echoed in later decades.\textsuperscript{20,25,46} The issue of study design and mortality and 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 reporting on the relocation of 529 patients from one nursing home to another in which they conclude that there is no adverse mortality effect from the relocation. Based on a review of the research they go on to conclude more generally that there is no support for a negative mortality effect from relocation. What followed was a series of published articles in which the Borup studies were criticised and defended. This debate was primarily around study design and review methodology and exemplified two aspects of the research, firstly the difficulty and secondly the passion associated with the "humanitarian concern" that underlies this issue. That mortality based research still continues with reports of both adverse mortality effects and no adverse mortality effects reflects the inconclusive nature of the debate.

One premise of the early work on the relocation effect was around what has been characterized as a "pure relocation effect". This suggests that it is the move itself, independent of factors preceding or following the move that leads to adverse effects. In his review Coffman found positive, neutral and negative effects of relocation consistent with a normal distribution of effects concluding that it is not the relocation itself. Coffman suggests that where adverse effects occur it is the factors surrounding the move that give rise to the relocation outcome and not 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 Coffman’s view that there are particular factors associated with the relocation that are responsible for the adverse effects of relocation, researchers have tried to identify those factors. Studies report that the following factors influence the outcome from relocation; involuntary rather than voluntary relocation; the degree of difference between the environment of the original location to the final destination; the degree of participation and choice by the person making the move; and the amount of support and preparation involved in the move process. In addition to these factors there is recognition by a number of researchers that there are different types of relocations that must be considered, these being home to institution, institution to institution and within the institution. More recently there is emerging research for relocations involving moves from retirement villages 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.

The discussion to date has focused on the quantitative literature. Emerging in the 1980s as a
significant line of enquiry is the literature based on qualitative approaches to research with one of
the first being a grounded theory study by Chenitz.\textsuperscript{67} 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{68} As part of the placement experience the researchers identify 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\textsuperscript{69} included 13 articles following their search phase. However this study was designed to
develop a transition model and did not summarise themes in relation to the experiences of older
people.

Qualitative studies since the Lee, Woo and McKenzie literature review report similar and
consistent themes. Couglan and Ward\textsuperscript{70} report themes of waiting, grieving the loss of personhood,
and the importance of relationships with family, staff and other residents. Tsai and Tsai\textsuperscript{71} report
themes of a temporary home, highly structured lifestyle, restricted activities, safety concerns and
relationships and Heliker and Scholler-Jaquish\textsuperscript{72} 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 comment "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{72}

No systematic review of the experiences of older people in relation to their move to residential
aged care was identified following a search of CINAHL, MEDLINE, and Google Scholar.

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.
CRITERIA FOR CONSIDERING STUDIES FOR THIS REVIEW

**Types of studies**

The review will consider qualitative studies that report on the experiences of older people who have recently (within the year prior the study) made a permanent move (relocation) into residential long term care.

Where a study includes 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 will be included however only the experiences of the older person will be extracted.

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. In the absence of research studies, other text such as conference proceedings, opinion papers and reports will be considered in a narrative summary.

Papers in languages other than English will be excluded.

**Types of Participants**

The review will consider the experiences of older people who have been admitted on a permanent basis to a residential long term care institution. The institution must be one that provides some level of personal or clinical care service and not just board and lodgings.

The review will not differentiate between studies involving subsets of older people (eg subsets based on specific morbidities such as dementia, ethnicity, gender or other specific differentiating characteristics). Should the data synthesis and analysis indicate differing results associated with subsets of older people these will be separately reported.

The review will be 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.
Definition of “older person”.

In developed countries there is no consensus as to an age delineator for “old age”. Denton and Spencer\textsuperscript{73} comment that the age marker of 65 has been regarded as the commencement of “old age” in developed countries for many years, while Foot and Fisher\textsuperscript{74} note that the medical literature commonly uses 70 and the World Health Organisation\textsuperscript{75} suggests that the “chronological age of 60 or 65” has been used in developed countries. 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”\textsuperscript{74} because ageing is a continuing process\textsuperscript{73} experienced differently by different people and the definition often arise out of the establishment of an official retirement age\textsuperscript{74}.

The circumstances of many people living in developing countries are significantly different with often much lower life expectancy rates\textsuperscript{76}. In view of this and while also recognising that the setting of any number for the determination of “old” is arbitrary the World Health Organisation\textsuperscript{75} 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{76} but when looked at in closer detail Aboriginal and Torres Strait Islander males have a life expectancy some 11.5 years shorter than non-indigenous males\textsuperscript{77}. The figure for females is a reported shorter life expectancy of 9.7 years. 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 will include studies of people from developed countries of 60 and of people from non developed countries of 50 where it is clear from the study this is appropriate. Where studies report on specific groups of older people within developed countries that are reported to have materially lower life expectancy than for that study country as a whole, then these studies will be included if the age criteria is clearly articulated and supported. The review will identify studies with differing age definitions.

**Phenomena of interest**
The phenomena of interest is the meaning and experience for older people of a permanent move into residential long term care institutions that provide personal and clinical care services.

**Context**

The study will include the experiences of a permanent relocation by older people from their home to a residential aged care facility. Because the review is looking at the impact of the move from a home in the community into a residential institutional setting relocations where the prior permanent living setting was an institution will be excluded. No exclusion will be made on the basis of culture or geographic setting however should material differences be observed these will be separately reported.

**Outcomes anticipated**

The anticipated outcome will be in the form of findings from a meta-aggregation of themes and categories arising from the data generated by older people and reported in relevant qualitative studies pertaining to the considerations, meaning and experience of moving into institutional long term care.

It is hoped the outcome of the study, through the rigours of the systematic review process, will provide a richer picture of the residential long term care experience from the view point of the older adult consumer of the service.
REVIEW METHODS

Search Strategy
The search strategy initially aims to find research studies published in peer review journals. The goal to use only published peer reviewed articles has been set to ensure the highest possible standard of evidence for the systematic review given the long and contested history of the area as outlined earlier in the protocol. A three-step search process will be utilised.

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

The second step will be an analysis of the key words contained in the title, abstract and index terms used to describe the articles identified in step one in order to establish a comprehensive keyword search list. Any new key words will be added to those already identified and recorded in Appendix I-Table 2.

The third search step will involve the review of the reference list of all relevant articles from step 2 to identify any other further relevant studies.

The databases to be used will be those containing peer reviewed and published articles. The databases to be 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 will be used.

For the CINAHL, MEDLINE and Scopus databases relevant thesaurus terms will also be used in the search process as part of step two. The thesaurus terms will be identified from the terms assigned by the particular database to the articles returned from the searches using the pre-prepared key words.

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

In the event there are insufficient studies from the above steps the search will be expanded to include grey literature sources (Appendix I, Table 4).

The search will include only English language studies.
**Assessment of Study Quality**

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standard critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). (Appendix II)

Any disagreement that arises between the reviewers as to the inclusion or exclusion of a paper will be resolved through discussion or a third reviewer.

**Data Extraction**

Qualitative data will be extracted from papers included in the review using the standardised data extraction tool from Joanna Briggs Institute Qualitative Assessment and Review instrument JBI-QARI. (Appendix III)

The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

**Data synthesis**

Qualitative research findings will, where possible be pooled using the Qualitative Assessment and Review Instrument (JBI-QARI). This will involve the identification of individual findings, supported by evidence, from the study (Level 1). The individual findings will be grouped, based on the similarity of their meaning, under differing category headings (level 2). Finally, the categories, again based on the similarity of meaning, will be used to generate synthesized findings (level 3) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.
POTENTIAL CONFLICT OF INTEREST

There are no known conflicts of interest.

It is noted that the primary investigator has previously worked in the aged care industry as a senior executive for more than twenty years.

Acknowledgements

As this review is undertaken towards a Masters in Clinical Science two reviewers were only used for critical appraisal.
REFERENCES:


33. Aneshensel CS, Pearlin LI, Levy-Storms L, Schuler RH. The transition from home to nursing


75. World Health Organisation. Definition of an older or elderly person [Internet]. [cited on 14th July 2010]. Available from URL: http://www.who.int/healthinfo/survey/ageingdefnolder/en/


## Appendix I

### Search Tables

#### Table 1

<table>
<thead>
<tr>
<th>Related to population</th>
<th>Related to phenomenon</th>
<th>Related to context</th>
</tr>
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<tr>
<td>over 65 elderly older adult</td>
<td>relocation transition admission move</td>
<td>nursing home long term care</td>
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#### Table 2

(Note: The search results will be combined and duplicates removed)

**Search combinations from table (where letter denotes column):**

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<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
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<tbody>
<tr>
<td>POPULATION</td>
<td>PHENOMENA</td>
<td>CONTEXT</td>
<td>EFFECT</td>
<td>RESEARCH TYPE</td>
</tr>
<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 adjustment admission admitted entry environmental change institutionalisation move moving to placement relocated/ing/ion resettlement transfer transition translocation</td>
<td>assisted living care-home conggregate 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 content analysis discourse ethnography ethnological ethno-methodology focus group grounded theory hermeneutic heuristic interpretive life experience lived experience meaning narrative observational perspectives phenomenological phenomenology purposive sample qualitative semiotics thematic analysis</td>
</tr>
</tbody>
</table>

1. A+B+E
2. B+C+E
3. A+C+E
4. A+D+E
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/MeSHline 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
## Appendix II

**QARI Appraisal instrument**

### Assessment for: Name of Assessment

**Type:** Primary  
**User:** qari

<table>
<thead>
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<th>Criteria</th>
<th>Yes</th>
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<tr>
<td>1) There is congruity between the stated philosophical perspective and the research methodology.</td>
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<td>2) There is congruity between the research methodology and the research question or objectives.</td>
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<td>3) There is congruity between the research methodology and the methods used to collect data.</td>
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<td>4) There is congruity between the research methodology and the representation and analysis of data.</td>
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<td>5) There is congruity between the research methodology and the interpretation of results.</td>
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<tr>
<td>6) There is a statement locating the researcher culturally or theoretically.</td>
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<tr>
<td>7) The influence of the researcher on the research, and vice-versa, is addressed.</td>
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<td>8) Participants, and their voices, are adequately represented.</td>
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<td>9) The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body.</td>
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<tr>
<td>10) Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data.</td>
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**Include:** Yes  
**Reason:**

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Appendix III

Quality Assessment Review Instrument (QARI) Data Extraction Instrument

**Extraction Details : Extraction Name**

Methodology:
Method:
Interventions:
Setting:
Geographical:
Cultural:
Participants:
Data Analysis:
Authors Conclusion:
Reviewers Comments:
Complete

[Update Cancel]