“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
29\textsuperscript{th} November 2011
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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