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Title

Is there an 'optimal time' to move to a care home for a person with dementia? A systematic review of the literature

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ABSTRACT

Background

There is limited evidence regarding how the decision evolves about whether and when it is best for a person with dementia to move to a care home. The factors leading to the timing of the decision remain particularly unclear. This systematic review of existing literature aims to gain an understanding of the decision-making timing and process to distinguish the drivers of these decisions, and to identify if there is an 'optimal' or best time (if any) for a person with dementia to move to a care home.

Methods

Six English language electronic databases were searched up to the end of 2016, along with included papers' reference lists. Papers were screened against the inclusion criteria and rated for quality. Extracted data were thematically analysed.

Results

The review identified 16 relevant papers. Seven themes were identified: 1) what happened before the move; 2) planning for the move, 3) weighing up the decision, 4) lack of support, 5) drivers of the decision, 6) emotional significance of the move, 7) continued reflection of the decision. 'Time' of the move was largely absent from much of the literature, although inferences were made. Overall, the decision-making process appeared to be cyclic, with family carers constantly re-evaluating when might be the time to make the move with some continuing to reflect on this even subsequently.

Conclusions

Further research is required to understand the 'optimal' or best time (if any) for when a person with dementia moves to a care home, and how to determine when someone is ready to move.

Key words: carers, care home, care-transition, decision-making, dementia, review

Running Title: People with dementia's moves to care homes

INTRODUCTION

When and whether a person with dementia should move to a care home is reported to be one of the most difficult decisions faced by many family carers (Elliott *et al.*, 2007; Elliot *et al.*, 2009). With increasing numbers of older people with dementia and limited social support, deciding when is the right time (if any) to move to a care home is a pertinent question. Indeed, one of the top research priorities identified by the Dementia Priority Setting Partnership between the UK Alzheimer's Society and James Lind Alliance (Alzheimer's Society 2013a) was "when is the optimal time to move a person with dementia into a care home setting?" The question indicates the pressing need to understand the decision-making process about care home moves and what enhances confidence in the timing of the decision.

The person with dementia is often cast as a passive agent in this moving process, with words such as "placed" and "abandoned" used (Sandberg *et al.*, 2001). A report by the UK think-tank DEMOS highlighted the fears that older people, people with dementia and the general public have about moving to a care home (The Commission on Residential Care, 2014). For many it appears that residential care is still 'the last resort' with limited options and very low expectations of care (Alzheimer's Society 2013b).

This systematic review of existing literature aimed to gain an understanding of the decision-making experience to distinguish what the drivers of decisions about residential care may be, and to identify if the literature indicated an 'optimal' or best time (if any) for a person with dementia to move to a care home. The review spanned two main subject areas regarding a person with dementia moving into a care home: (1) reasons for the move and how these decisions are made, and (2) the timing of the move.

METHODS

Inclusion criteria

Studies included in this review were international studies in English language, up to December 2016, that described the experience of moving to a care home from their own home, from the perspectives of people with dementia, family carers, and professionals. We focussed specifically on inductive studies that elicited rich descriptions of the decision-making process. Only empirical primary research was considered; therefore, editorials, opinion pieces and

letters were excluded. Literature reviews were not included but their primary studies were considered. Papers were also excluded if:

- the person with dementia did not move (or plan to move) from their own home to a care home.
- people with dementia (or their family carers) could not be distinguished from other participants in the study sample.
- a deductive approach was used, which included studies that only focused on the predictors or risk factors of a person with dementia moving to a care home (including clinical drug trials).
- the findings from the qualitative element of a mixed methods study could not be distinguished from the quantitative data.

Search procedure

Six English language bibliographies were searched for relevant national and international literature: Cumulative Index to Nursing and Allied Health Literature (CINAHL; EBSCO), EMBASE (OVID), PsycINFO (OVID), PsycARTICLES (OVID), Social Policy and Practice (OVID), MEDLINE (OVID and EBSCO). No date restrictions were imposed, and papers were searched up to the date of the search (December 2016). To establish relevant search terms, the mnemonic PICO (Participant, phenomenon of Interest, Context) was used. PICO is a recognised tool for searching literature systematically (Joanna Briggs Institute, 2011). Consequently, the derivatives and variations of the following search terms were used: 'Dementia' (Participants) AND 'decision-making' (phenomenon of interest) AND 'move' (phenomenon of interest) AND 'care home' (context). Examples of terms used in the search are provided in Table 1. In addition to the database search, the final included papers' reference lists were hand searched for relevant papers meeting the inclusion criteria.

[Table 1: to be inserted here]

All titles and abstracts from the final search were screened against the inclusion criteria. Full texts of selected papers were then screened, and finally, included papers were identified. Screening was initially completed by one researcher (author 1), and included papers were

selected and agreed upon by the three authors (author 1, author 2, author 3). Included papers were subject to data extraction (author 1). This involved extracting data in a systematic way from each paper, using the inclusion criteria summarised in Table 2.

[Table 2: to be inserted here]

Definitions

In England, the term 'care home' refers to long-term care facilities providing care and support (Orellana, Manthorpe and Moriarty, 2016). Care homes are sub-divided into care homes with nursing, which are required to have a registered nurse on duty at all times, and care homes, often referred to as residential homes, which do not employ registered nurses. However, many different terms are used for these facilities, which vary internationally (e.g. Sanford *et al.*, 2015). For this review, long-term institutional care, care homes (with and without nursing support), nursing homes, residential homes were included. We were particularly interested in the permanent move made from home to a long term care facility providing 24-hour care, where an individual would consider themselves to be a resident. For this reason assisted living facilities, sheltered housing, or retirement villages were not included, as these are often transitional settings before a move to a long-term care facility, where individuals consider themselves to be in their own private home and not sharing with other 'residents'. The term 'carer' is used in this paper to mean family member or friend providing care and support; often also referred to as a caregiver.

The review did not discriminate between young onset and later onset dementia; and studies were not eliminated based on dementia diagnosis (e.g. Korsakoff dementia). Studies were included that covered people with all types of dementia.

Assessment of quality

An assessment of quality was performed on each paper meeting the inclusion criteria for this search. The QualSyst scale (Kmet *et al.*, 2004) was used for this purpose, as it has protocols for both qualitative and quantitative methodologies. The scale consists of ten criteria, which evaluate the appropriateness of the study design, clarity and justification of the methods used, and the credibility of the study. Each criterion is scored as met (2), partially met (1) or

not met (0). A total percentage is gained for each paper (score / possible score x 100). Consequently, higher percentages indicate high quality papers. The authors of the QualSyst scale used a threshold of 55% for inclusion of papers. Consequently, for this review, authors identified papers having a total score of 55% or lower as low quality and not included in the review. Papers scoring between 55% and 69% were considered 'adequate', and those 70% and above being of good quality. All papers were independently rated by (author 1) and then a quarter was second rated by (author 2). Two papers gave rise to discrepancies between researcher scores; these were discussed and resolved between researchers (authors 1, 2 and 3).

Analysis

Each paper was thematically analysed. All text and tables in the results and discussion sections of included papers were considered data. Commonalities in relation to circumstances and factors that affected the decision to move to a care home or timing of the move were coded. These codes were grouped into larger themes and two researchers (author 1, author 2) discussed the appropriateness of emergent themes. A third researcher (author 3) provided verification on the decision. A summary of appraisal scores is displayed in the final column of Table 3.

[Table 3: to be inserted here]

RESULTS

Search results: characteristics of studies, and assessment of quality

A total of 744 papers were found in the search, and after 185 duplicates were removed, 559 titles and abstracts were screened, and 394 were excluded. The full text of potentially relevant papers was retrieved and screened against the inclusion and exclusion criteria. A further 141 papers were excluded, and four papers were unavailable. The remaining papers were rated for quality. In total, 21 papers were included in the review, which documented 20 studies. The process of screening and selecting papers is illustrated in the flow-diagram, Figure 1.

[Figure 1: to be inserted here]

Nearly all papers were published between 2001 and 2016; four papers were published in the 1990s. The majority were from the United States (US) (n=5); with other contributions from Australia (n=5), the UK (n=4), Canada (n=4), Korea (n=1) and Taiwan (n=1). Two papers were from the same study (Chang and Schneider, 2010; Chang *et al.*, 2011).

All studies used semi-structured or in-depth interviews in their methodology. Duncan (1992) was the only study to additionally use focus groups. Three studies included people with dementia in their sample: of these two exclusively interviewed people with dementia (Aminzadeh *et al.*, 2009; Thein *et al.*, 2011) and one involved people with dementia and family carers (Lord *et al.*, 2016). Only one study included the views of a professional (a social worker) alongside a carer (Mamier and Winslow, 2014). All other studies (n=16) sought the views of carers alone. The majority of the studies asked participants about their experiences of the move retrospectively (n=7); three were prospective experiences, and five were mixed (participants who had already moved and those about to move). Five studies interviewed participants before and after the move. Nineteen papers were of good quality, and two studies were of adequate quality (Ashton *et al.*, 2016; Mamier and Winslow, 2014); consequently, no papers were excluded on quality. Characteristics of the included papers are summarised in Table 4. Characteristics of the individuals involved in the studies (i.e. people with dementia, carers and professionals) are summarised in Table 5.

[Table 4: to be inserted here]

[Table 5: to be inserted here]

Thematic Analysis

Findings from the review revealed seven overarching themes that described the decision-making experience connected with the move of a person with dementia to a care home: 1) what happened before the move; 2) planning for the move, 3) weighing up the decision, 4) lack of support, 5) drivers of the decision, 6) emotional significance of the move, 7) continued reflection on the decision. A summary of these themes is presented in Table 6.

[Table 6: to be inserted here]

1) WHAT HAPPENED BEFORE THE MOVE?

Reasons for the move to a care home were often declared complex and not due to just one factor. The metaphors of ‘tipping points’, ‘triggers’ or ‘breaking points’ were described as the time at which factors culminated or were combined such as to necessitate a move to a care home (Butcher *et al.*, 2001; Crawford *et al.*, 2015; Lord *et al.*, 2016). Often contextual factors influenced the decision to move to a care home (Caron *et al.*, 2006). Among the many different reasons were: a crisis event; worsening symptoms of dementia or general health of the person with dementia; and carer perception of being unable to cope. Each of the themes is inter-related.

Crisis event

Crisis events most often involved a hospital admission (Ashton *et al.*, 2016; Cahill, 1997; Caron *et al.*, 2006; Chene, 2006; Crawford *et al.*, 2015; Duncan, 1992; Mamier and Winslow, 2014; Strang *et al.*, 2006). Sometimes the need for a move to a care home was framed as ‘medical’ following a hospital admission, as it was not considered viable or practicable (due to the environment and adaptations required) for the person with dementia to return home (Caldwell *et al.*, 2014). A crisis could also be an indicator to the carer that the person with dementia’s cognitive decline had reached a critical point (Butcher *et al.*, 2001) that was now unmanageable. Up until this time, the carer may have not noticed the slow gradual cognitive changes (Strang *et al.*, 2006).

Worsening symptoms of dementia or general health of person with dementia

Carers often evaluated the reasons for the move, they cited the safety of the person with dementia as one of the main reasons for the move to a care home (Butcher *et al.*, 2001; Caldwell *et al.*, 2014; Lord *et al.*, 2016; Mistic, 2008; Park *et al.*, 2004). Concerns around falls, misuse of electrical equipment and lack of safe environments were the main risks identified (Duncan, 1992; Lord *et al.*, 2016); and similarly worries about monitoring medication, falls, and accidents (Caldwell *et al.*, 2014) were reported as ‘triggering’ factors. Such concerns could lead to a carer feeling that they needed to be always present to ensure the person with dementia’s safety (Butcher *et al.*, 2001) and also to appease the person with dementia’s

anxiety (Crawford *et al.*, 2015); not surprisingly this negatively affected the carer's wellbeing (Crawford *et al.*, 2015; Mamier and Winslow, 2014). Alternatively, some carers were concerned about their own safety when in the presence of the person with dementia due to their challenging behaviours (Park *et al.*, 2004). The person with dementia's behaviour sometimes seemed so unmanageable that it negatively affected the carer's (Cahill, 1997) and the whole family's well-being (Chang and Schneider, 2010). Examples of behaviours which affected this decision were: swearing, aggression, wandering, sleeplessness, and the carer's inability to reason with the person with dementia (Armstrong, 1999; Chang and Schneider, 2010; Mistic, 2008). Duncan (1992) found that negative changes in the person with dementia's behaviour were more difficult for adult-children to cope with than for spouse carers, and the former were more likely to cite these as the reason for seeking a move to a care home.

When people with dementia were consulted, they identified their functional and physical difficulties as reasons for a move to a care home, attributing this to their age and not to their cognitive problems (Aminzadeh *et al.*, 2009; Thein *et al.*, 2011). For those who realised their own difficulties (such as the need for monitoring or watching over), this made it easier for them to come to terms with the idea of moving to a care home (Lord *et al.*, 2016; Thein *et al.*, 2011).

Some carers attributed the person with dementia's physical problems as a reason for moving to a care home. As other studies noted, concerns included falls, but also pain or the difficulties of making adjustments to the home (Caron *et al.*, 2006; Lord *et al.*, 2016), which could further change over time (Caron *et al.*, 2006). Carers found managing multiple co-morbidities difficult. For example, the onset of urinary and faecal incontinence was a specific trigger that made some carers feel that caring had now become impossible (Armstrong, 1999; Cahill, 1997; Caldwell *et al.*, 2014; Duncan, 1992).

Generally, carers were uncertain about the future rather than thinking there was a known care pathway. They realized that something was wrong and recognised the person with dementia's health problems (Butcher *et al.*, 2001). However, due to the progressive but

unpredictable nature of the dementia, carers did not know what the future would entail for themselves, the person with dementia, or the caring situation (Lord *et al.*, 2016).

Carer recognition of being unable to cope

Contextual influences that changed or accumulated over time meant that carers faced the possibility of the person with dementia moving to a care home in order to ensure their care needs were being met (Caron *et al.*, 2006; Crawford *et al.*, 2015; Duncan, 1992; Mamier and Winslow, 2014). Carers decided that they were unable to cope with caring for the person with dementia at home on the basis of two main reasons: their own health problems and the stress of caring.

Some carers were unable to continue to care for the person with dementia at home due to their own physical health problems (Armstrong, 1999; Butcher *et al.*, 2001; Cahill, 1997; Caldwell *et al.*, 2014; Chang and Schneider, 2010; Chene, 2006; Lord *et al.*, 2016; Mistic, 2008). This seemed of particular significance for spouse carers who could also be experiencing their own age-related illnesses (Chene, 2006; Lord *et al.*, 2016). The stress of caring for a family member with dementia resulted in some carers feeling emotionally and physically exhausted (Cahill, 1997; Duncan, 1992), causing social withdrawal and weight loss (Armstrong, 1999; Pierre-Louis, 2012). However, some carers did not seem to acknowledge or accept that they could no longer emotionally and physically cope with the care of the person with dementia, and it was their own health care practitioner who had instigated the need for the person with dementia to move to a care home for the sake of the carer's health (Pierre-Louis, 2012).

Carers' perceptions of their own ability to continue to care for the person with dementia were an important factor, as many carers were apprehensive about their current caring situation. Some carers felt they had learned to care for their relative through trial and error, but felt out of control as the person with dementia's care needs grew (Park *et al.*, 2004) and some worried about their continued ability to meet their relative's physical and emotional needs (Ashton *et al.*, 2016; Mistic 2008; Strang *et al.*, 2006). Taking on new roles and responsibilities within the household contributed to the stress of the caring situation (Butcher *et al.*, 2001; Park *et al.*, 2004). Carers reported arguing with the person with dementia and having no time for

themselves (Caldwell *et al.*, 2014; Mistic 2008). A history of “anger, sadness, frustration and distress” made carers also feel unable to cope (Tilse, 1998, p. 32). In one study, a carer reported that feeling unable to cope made them fear physically harming the person with dementia through overwhelming feelings of frustration (Park *et al.*, 2004).

2) PLANNING FOR THE MOVE

In planning for a possible move to a care home, some carers recounted how they had explored alternative care options. This exploration sometimes reflected the carer’s stage of ‘readiness’ for the person with dementia to move from their home to a care home.

Available alternatives to a move to a care home

Alternative or rather supplementary additions to a carer’s support for the person with dementia were sought from a variety of sources, such as family, friends, and professionals (Caldwell *et al.*, 2014). Options considered included: moving the person with dementia to live with an adult child (Caldwell *et al.*, 2014; Pierre-Louis, 2012), acquiring extra home care assistance (Caldwell *et al.*, 2014; Duncan, 1992; Lord *et al.*, 2016), arranging ‘meals on wheels’ (home delivered meals), taking up a place in a day centre to give the carer a break (Caron *et al.*, 2006) or a day hospital, or arranging a short-stay in a geriatric unit. However, the financial costs of these often meant that they proved problematic or not viable (Caldwell *et al.*, 2014). In addition, carers often felt that there would ultimately be a time when this level of care would not be enough for their relative with dementia (Caldwell *et al.*, 2014).

Residential respite or short-break services were viewed by many as a step towards long-term care (Caldwell *et al.*, 2014; Mamier and Winslow, 2014), and an effective strategy for the person with the dementia and the carer to get used to the idea of the move from home. However, this was only if the respite experience was a positive one and suited the person with dementia’s needs (Caldwell *et al.*, 2014). Not all carers had been offered respite care and some stated that they would have liked government assistance or interventions (Park *et al.*, 2004).

Waiting list option

Carers sometimes perceived their relative's place on the waiting list of a care home as a viable and positive option (Cahill, 1997; Caldwell *et al.*, 2014; Duncan, 1992; Strang *et al.*, 2006). Although not quite ready to relinquish their care responsibilities completely, asking to go on a waiting list seemed to be a first step to recognising that a move to a care home may be required eventually (Caldwell *et al.*, 2014). Some carers were ready but anticipated a long wait until a room in a particular care home became available and wanted to prepare for the time when they could no longer cope with caring for the person with dementia at home (Caldwell *et al.*, 2014). Such limited care home vacancies meant that for some a care home place was not available at the point that they needed one and were ready for the move to be made (Duncan, 1992; Strang *et al.*, 2006).

Carers' readiness to make the decision

Ultimately, carers said they needed to feel prepared and ready for the move (Butcher *et al.*, 2001; Mamier and Winslow, 2014). Several factors needed to align for 'readiness' to be determined: such as both the carer and person with dementia realising that care at home was no longer sustainable (Caldwell *et al.*, 2014). Hagen (2001) found six inter-related factors affecting the ability of carers in their study to make a decision about a move, and therefore their readiness for the move: 1) independence in their relationship to the person with dementia, 2) perceived support from others, 3) feelings of guilt, 4) sense of existential self, 5) fear of loneliness after placement, and 5) negative views of care homes (Hagen, 2001). As noted, synchronicity was also important, such as a place in the home being available at the same time as the carer being ready (Strand *et al.*, 2006).

Park and colleagues found that carers weighed up the responsibilities of caring for others in the family (including themselves) with the person with dementia's needs as part of determining their readiness for the move (Park *et al.*, 2004). In addition, carer readiness was determined by a "gut-feeling" and "intuition" which was termed by authors as a form of self-support (Duncan, 1992, p. 70).

From a professional point of view, there is an indication from one US case study (covering one carer and one social worker) that social workers may consider it their role to help carers emotionally come to terms (be ready) with their family member's dementia diagnosis

(Mamier and Winslow, 2014). However, they found that this particular social worker's and carer's point of 'readiness' did not coincide. The carer was ready for the move but the social worker did not realise this. At this critical time, the carer was concerned about finances, while the social worker was concerned about the carer being emotionally ready for the move and separation.

3) WEIGHING-UP THE DECISION

Carers considered the 'anticipated consequences' for all family members involved, should the person with dementia move to a care home, before making the final decision (Caron *et al.*, 2006) and needed to feel confident about making the right choice. The decision to move to a care home was evaluated over time with some concluding that 'now' was not the best or right time for the person with dementia to move.

While there is very limited evidence from professionals' point of view, one US case study, reported a social worker positioning herself in a neutral position, to be able to assist the family carer in making their decision (Mamier and Winslow, 2014).

Finances

Paying for care was found to be a significant factor in the decision-making process for some carers (Chang, *et al.*, 2011; Mamier and Winslow, 2014) and people with dementia (Lord *et al.*, 2016). Carers with limited finances found the decision more "challenging and frustrating" (Chang *et al.*, 2011, p.439) and in one case financial problems had delayed the decision (Mamier and Winslow, 2014). The decision about the 'place of care' was hugely influenced by the finances available to the carer and the person with dementia. Carers were concerned about the cost of a 'good' care home (Chang and Schneider, 2010; Duncan, 1992), with some saying they accepted a care home place that they could afford but then worried about its quality of care (Chang and Schneider, 2010). Carers' decisions centred around finding the best care home for the cheapest price, and some were 'savvy' or knowledgeable that care homes with a 'lavish' exterior did not "always mean the best" (Duncan, 1992, p. 73).

Making the decision about a care home move also initiated a conversation about payment sources and difficult debates about using a parent's hard-earned money to pay for their care.

Additionally, spending a parent's money in this way would affect the size of the adult child's inheritance, potentially causing some family conflict (Duncan, 1992).

Park and colleagues found that carers who gave up work to care for their relative full-time, quickly ran out of money and had to resume employment to support the family. It was this return to work that necessitated the person with dementia's move to a care home (Park *et al.*, 2004). In one case study financial considerations and strains were present throughout the decision-making process and continued after the care home move (Mamier and Winslow, 2014). Lack of information about the different financial options and resources available from the government increased carer burden (Chang *et al.*, 2011).

A care home move is considered a last resort

All carers in Lord and colleagues' (2016) study expressed a desire for their relative with dementia to stay in their own home for as long as possible; with many carers from this and other studies (Caldwell *et al.*, 2014; Duncan 1992) stating that they were able to manage this and viewing a move to a care home as a last resort. Carers considered it important that the person with dementia's home surroundings were familiar to them and that the person could continue their usual daily activities and routines (Lord *et al.*, 2016). Likewise, carers in Caldwell *et al.*'s (2014) study stated: "*It's just too early stage . . . going to nursing home is just like going to jail*" (Caldwell *et al.*, 2014 pg. 418). These comments were related to negative perceptions of care homes as being of poor quality care, restrictive of autonomy and rights (Caldwell *et al.*, 2014) and the feeling that this would be their final home (Chene, 2006), and "a place to wait for death" (Chang *et al.*, 2011, p. 440). Carers with negative attitudes towards care homes seemed to find the decision-making process particularly difficult (Hagen, 2001). Carers saw care home placement as a last resort if the person with dementia was reluctant to move due to fears of poor quality care, from past experiences or perceptions of care homes, sometimes linked to cultural or historical standards of poor care (Caldwell *et al.*, 2014).

4) LACK OF SUPPORT

Carers stated that they did not know where to turn to in order to gain support; they felt as though they did not "*know all the questions to ask...*" (Lord *et al.*, 2016, p. 5). They were

generally unaware of available services and felt unable to negotiate health and social care systems (Lord *et al.*, 2016).

Peer and professional support

Carers acknowledged that the “presence or absence of support” influenced the decision-making process (Butcher *et al.*, 2001, p. 476; Caron *et al.*, 2006; Hagen, 2001). A perceived lack of support was a major indicator for a move to a care home (Park *et al.*, 2004). Support from a peer-group was thought helpful in providing guidance and in hearing of others’ experience (Duncan, 1992); although carers may not always want to attend a group throughout the whole transition (Mamier and Winslow, 2014). A frequent finding was that carers often did not feel as if they had access to sufficient information about possible different options or alternatives to a care home (Ashton *et al.*, 2016; Butcher *et al.*, 2001; Chang and Schneider, 2010; Chang *et al.*, 2011; Park *et al.*, 2004). Having someone to listen to carers’ needs, understand their problems, and explain information was considered vital (Armstrong, 1999).

The idea of developing a decision aid that focused on the future place of care for a person with dementia was considered by carers and people with dementia in one study to be a potentially extremely beneficial tool (Lord *et al.*, 2016). However, it was thought that such an aid should not just focus on a move to a care home but should contain options and information about other alternatives types of care. Participants in that study also wanted information on the ‘changes that may occur’ that might influence the decision (e.g. change in carer’s health). How to access helping organisations and the remit of these agencies were also thought potentially useful information. They thought the decision aid should be delivered by a professional, face-to face, as the need for human interaction would be imperative. All participants agreed that this aid should not be provided at the point of diagnosis but the time should be determined by a supportive professional (e.g. a clinician at a memory clinic) (Lord *et al.*, 2016).

Inadequate services

Carers receiving services often considered them inadequate for their needs (Caron *et al.*, 2006) and should: “a) be available and accessible, b) be flexible, c) be continuous and co-

ordinated among the various service providers, and d) have an acceptable waiting time for services, without unreasonable delays” (ibid p. 199). In another study, carers felt that they were offered help at the wrong times of the day, and generally support was offered when it was not needed. They felt that the provision of 24-hour help, or at least night-care would have been more supportive, and could have even prevented a care home move (Armstrong, 1999). In addition, in order for professionals to be supportive to carers in the decision-making process they should be “empathic, supportive and accessible” (p. 200) and be positive about the abilities of the carer to care for the person with dementia (Caron, 2006).

Choosing the right care home

Generally, carers expected their family member with dementia’s basic care needs to be met whilst in the care home (Mistic, 2008). Desirable care home characteristics from the perspectives of carers included being clean, spacious, illness related, and staff to be friendly/caring/communicative, , and trained, personalised care, a homely environment (Butcher *et al.*, 2001, Mistic, 2008), no smell, being culturally appropriate (Ashton *et al.*, 2016), and where their family physician or general practitioner could continue to act as the person’s doctor (Caldwell *et al.*, 2014). Other desirable considerations were location; being near friends and other relatives (Ashton *et al.*, 2016; Lord *et al.*, 2016), and the organisation and management of the care home (Duncan, 1992, Mistic, 2008). In addition, some family carers applied early for a culturally appropriate care home, or one with a good reputation (e.g. an “ethno-specific” care home; Caldwell *et al.*, 2014, p. 418). Korean family carers were described as lacking experience of long-term care and therefore were unsure about their options, or how to control the situation (Park *et al.*, 2004).

Carers in one UK study had been provided with a list of care homes by their social workers, and given the task of choosing a care home for their relative with dementia (Ashton *et al.*, 2016). They described feeling like ‘inspectors’ walking round care homes, and felt ill equipped to make such an important choice (Ashton *et al.*, 2016). Receiving assistance in a hospital setting in choosing an appropriate care home was a diverse experience; carers in Crawford’s (2015) Australian study had positive experiences with hospital staff and social workers, conversely, the carer in the Mamier and Winslow’s (2014) US case study felt she did not

receive enough support from the hospital social worker. Generally, carers felt that there was little professional support when choosing a care home (Chang *et al.*, 2011) and navigating procedures to secure a place (Cahill, *et al.*, 1997).

Sometimes, however, there was little choice of a care home, which may be due to the limited numbers of care homes providing specialist dementia care (Chang *et al.*, 2011; Cahill, 1997). Some people with dementia may not be accepted by a care home if the home feels it cannot support their needs such as those arising from severe behavioural and psychological symptoms of dementia (Chang *et al.*, 2011). Alternatively, there may be some urgency to take up an offer of an available bed in a care home. This could be a pressure if the person with dementia needed to be discharged from hospital and it was not feasible to return home. It could result in accepting the 'next best' option (Duncan, 1992).

5) DRIVERS OF THE DECISION

Family negotiations – decision maker roles

Many carers considered moving a person with dementia to a care home was too large a decision for them to make alone and generally sought the opinions of other family members (Ashton *et al.*, 2016; Chang and Schneider, 2010; Chang *et al.*, 2011; Lord *et al.*, 2016; Strang *et al.*, 2006). In Mistic's study, family members were influential in the decision-making, but the primary carers had the ultimate, final decision on whether the move to a care home should occur (Mistic, 2008). Families understood the need to move to a care home if they were involved with caring and supported the carer (Duncan, 1992). This was particularly the case among adult children (Duncan, 1992), when a primary carer was not easily identified (Caron *et al.*, 2006), or when carers felt that they had to make the decision on behalf of the person with dementia, as they no longer had the necessary cognitive abilities or insight to make such a decision for themselves (Lord *et al.*, 2016). Spouses were found in Duncan's (1992) study to be responsible for the decision rather than other family members.

Carers often found the shift to their new role as decision maker difficult and somewhat overwhelming (Lord *et al.*, 2016). For spouses, a decision not made jointly led to feelings of guilt and betrayal of their marital vows (Tilse, 1998). Moving to a care home, if not via hospital, especially felt like a rejection (Tilse, 1998). Carers felt alone in the decision-making process as

the person with dementia was not able to contribute (Chene, 2006) or corroborate the decision (Duncan, 1992; Tilse, 1998). Lord and colleagues noted that none of their participants could draw on formally expressed statements of wishes made in advance by the person with dementia (Lord *et al.*, 2016). However, carers seemed to find the decision easier if they had some independence in their relationship with the person with dementia. Difficulties occurred when the relationship with the person with dementia was more enmeshed (Hagen, 2001).

Not surprisingly, conflict made the decision difficult and complicated the process further (Butcher *et al.*, 2001; Chang and Schneider, 2010). Conflict was reported to occur if it was difficult to bring up the subject of a move (initiating the decision), or the need for a move to a care home was disputed between family members, which could delay the final decision (Caldwell *et al.*, 2014; Park *et al.*, 2004). Chang and Schneider described three types of family decision-making: 1) consensual – family members and the main carer are in agreement about the move; 2) partial consensual – the family are not in full agreement with the move but the main carer decides on a move; 3) reluctant – the main carer does not agree with the move but is persuaded by family members (Chang and Schneider, 2010). Family disagreements could damage relationships between family members (Cahill *et al.*, 2011; Chang *et al.*, 2011). Two thirds of the carer sample in Park *et al.*'s (2004) Korean study said that their relationship with their family members was already strained due to caregiving, and that this worsened due to conflicts in the decision-making process (Park *et al.*, 2004). Family disagreement and tense relationships were reported to remain after the person had moved to the care home (Chang and Schneider, 2010).

Person with dementia and decision-making

The 'willingness' of people with dementia to move to a care home was a crucial factor in the decision-making process (Chang *et al.*, 2011; Chene, 2006). Deciding whether to involve the person with dementia was difficult as carers feared they would not want to move (Chang *et al.*, 2011). Some carers described how it was the person with dementia's wishes not to move, to stay living in their own home, and the immense pain this caused in going against their wishes (Chang *et al.*, 2011; Chene, 2006). Two people with dementia had threatened self-harm if they were moved to a care home (Chene, 2006). Reciprocity in the relationship between the person with dementia and the carer was affected by past and present

relationships and current circumstances and ability to make decisions (Duncan 1992). If the expectations of the person with dementia differed from those of their carers then the decision became problematic (Caldwell *et al.*, 2014; Strang *et al.*, 2006).

In Caron and colleagues' (2006) study, carers said, where possible, the person with dementia had been involved in the decision-making process (according to their abilities). However, if the person with dementia over-estimated their ability to stay safe and well at home then their decision-making abilities could be brought into question, which could cause conflict (Caron *et al.*, 2006).

A UK study was one of the few to interview people with dementia and carers on this topic; here the majority of people with dementia reported that they had not been supported enough to make their own decision and resented being excluded from the decision-making process (Lord *et al.*, 2016). Participants described being "*taken over*", having "*no control or influence*" and "*forced*" into the decision (Lord *et al.*, 2016, p. 3). People with dementia questioned the 'rights' of others (e.g. family members, professionals) to make these decisions on their behalf. However, others were happy that the decision had been shared with their members of their family (ibid).

In one of the few studies that interviewed people with dementia before and after their move to a care home, most people with dementia considered a visit to a care home as an important part of the decision-making process (Thein *et al.*, 2011). However, only a few people with dementia indicated that they had made such a visit before their move (although it was noted that others may have forgotten their visit) (Thein *et al.*, 2011).

6) EMOTIONAL SIGNIFICANCE OF THE MOVE

Carers thought that making the decision was unavoidable (Butcher *et al.*, 2001; Caldwell *et al.*, 2014), yet a difficult and painful experience (Butcher *et al.*, 2001; Caldwell *et al.*, 2014; Chang and Schneider, 2010; Chang *et al.*, 2011; Crawford *et al.*, 2015; Hagen, 2001). Tilse's (1998) study found that moving a person with dementia to a care home was more difficult than moving a person with physical problems because of the 'meaning of the move'. For

people with dementia, the move was typically due to the carer no longer being able to cope with behaviours that challenged, as opposed to an increase in health needs, which made the move seem more personal.

The 'meaning of the move' was of concern to the professional and the carer in the US single case study (Mamier and Winslow, 2014). The social worker tried hard to make the carer understand that moving her spouse with dementia to a care home did not mean rejection. However, the carer was guilt-laden as she felt that she was giving up the 'fight' of dementia and this conflicted with her marriage vows (Mamier and Winslow, 2014).

The meaning of the move from the person with dementia's perspective meant an end of an era, leaving the home behind. It was a time to have some rest: *"Just kick off your shoes and your meals are ready and your place is clean and it means so much"* (Aminzadeh *et al.*, 2009, p. 490). Similarly, moving to a care home meant being cared for, having company, being relieved of daily chores (Thein *et al.*, 2011). However, there was some anticipation that the move would entail some loss of independence and that their world would be slightly more restrictive (Aminzadeh *et al.*, 2009; Thein *et al.*, 2011). Those with more severe cognitive impairment were more anxious and apprehensive about the impending move, which in this Canadian study was about two months prior to the planned relocation (Aminzadeh *et al.*, 2009). Of the 16 people with dementia interviewed most felt that they would draw from their own rich past and life experiences, their personal characteristics and resources that they had accumulated over the years to deal with the change in their living situation (Aminzadeh *et al.*, 2009).

In Thein and colleagues' study (2011); one participant thought that it might be depressing to live with other older people, which seemed to reflect common stereotypes about care homes. However, even those who were hesitant about how they would fit in to their new surroundings remained predominantly positive about the move (Aminzadeh *et al.*, 2009).

7) CONTINUED REFLECTION ON THE DECISION

A final theme included the continued reflections on the decision, including continuation of the caring and kin relationship, and the emotional responses moving evoked.

Continuation of the caring and kin-relationship

Visiting the family member in the care home was described as a difficult experience by some carers (Pierre-Louis, 2012; Strang *et al.*, 2006; Tilse, 1998). However, carers wished to remain involved in their relative's care as the familial relationship continued, albeit in a different context (Butcher *et al.*, 2001; Strang *et al.*, 2006). For one, this meant working with the care staff (Mamier and Winslow, 2014). Establishing a good relationship with care staff at the care home was identified by carers as an important adjustment to the new situation (Duncan, 1992). However, conflict between staff and carers was sometimes brought about by the differences in how the person with dementia was formerly (carer's knowledge) and how the person was now (staff encouraging family member to accept the current presentation of the person with dementia) (Tilse, 1998, p. 32).

Losing control of the care of the person with dementia was problematic for some carers, as they expressed their concern about what was happening to their relative when they were not there visiting (Crawford *et al.*, 2015; Strang *et al.*, 2006). An early study described this as "trying to hold on while letting go" (Duncan, 1992, p. 77).

Carers wanted the person with dementia to be cared for better than when they were at home (Butcher *et al.*, 2001; Caldwell *et al.*, 2014). This meant with dignity (Strang *et al.*, 2006), and with their care needs being met (Ashton *et al.*, 2016). Negative experiences around the time of the move were further heightened when carers thought that they were not receiving as much care, or the best quality of care as they had originally thought, and had to readjust their expectations (Chang and Schneider, 2010; Chang *et al.*, 2011). Consequently, carers changed their care role and took on the responsibility of assessing the environment, the person with dementia, staff and management of the care home (Duncan, 1992). Carers constantly evaluated and monitored the quality of care, which included the staff's behaviours and interactions with other residents in the care home, and assessed whether their relative appeared to be content and happy in their new home (Butcher *et al.*, 2001; Chang and Schneider, 2010; Duncan, 1992; Strang *et al.*, 2006). If they perceived the quality of life of the person with dementia in the care home to be poor, or the person with dementia's health or cognition to have deteriorated, they tended to blame themselves for this decision-making

and abandoning their family member (Chang *et al.*, 2011). From the person with dementia's perspective, being visited by family members was of great benefit to them, and they observed how these visits helped their family member too (Thein *et al.*, 2011).

Emotional responses following the move

Carers' emotional responses after the person with dementia had moved to the care home seemed largely related to individual beliefs and values (Duncan, 1992). Some studies report that care for one's parents and elders in old age is a commitment that is very strong in some cultures, especially in Asian societies where this is often referred to as 'filial piety' and to not do this is abandonment or a 'sin', as they feared what others would say (Chang and Schneider, 2010; Chang *et al.*, 2011; Park *et al.*, 2004). This moral obligation to care was also noted in Pierre-Louis' (2012) study of African-American daughters. However, with the changing dynamic of the family and Western influences, the studies suggest there is a shift in this thinking, as many families struggle to cope with the competing demands and responsibilities of the younger members of the family, balancing providing care with work, finances and the needs of younger dependents. Consequently, new definitions of 'filial piety' may be created to fit current social norms (Caldwell *et al.*, 2014; Chang and Schneider, 2010; Park *et al.*, 2004). Nonetheless, Korean carers were concerned about what others outside of the family would say about not looking after one's parents as common perceptions were that moving a person to a care home was "inhumane", "immoral" and seen as "dumping a parent" (Park *et al.*, 2004, p. 353). In this study some carers had traumatic memories of the move, recalling their distress at seeing locked doors and windows in the home (Park *et al.*, 2004). Feelings of guilt and shame were intense among some carers elsewhere (Butcher *et al.*, 2001; Caldwell *et al.*, 2014; Park *et al.*, 2004); for example, those who stated that the person with dementia had never wanted to move to a care home (Armstrong, 1999). When guilt was felt about the decision to move the person to a care home, carers looked to justify their decision by demonstrating the need for specialist care or the move being a physician's decision (Mistic, 2008). However, while feelings of shame, especially among adult children, were reported, others acknowledged mixed feelings: "In the guilt, I feel relief" (Duncan, 1992, p. 83; Mistic, 2008; Pierre-Louis, 2012).

“Intensive self-questioning and self-reflecting” (Park *et al.*, 2004, p. 351), asking themselves if they had done the right thing (Strang *et al.*, 2006 Mistic, 2008), and seeking reassurance about the decision made (Butcher *et al.*, 2001) were also reported. Other family members were not always available to offer reassurance about the decision made, so the burden of the decision lay with the carer (Strang *et al.*, 2006). However, carers did not feel as much guilt if the decision to move the person with dementia to a care home had been initiated by a professional (Caron *et al.*, 2006; Pierre-Louis, 2012).

Loss and grief

Spouse carers described how they found it difficult to live alone at home once the person with dementia had moved, as they felt lonely, loss, and without a sense of purpose (Crawford *et al.*, 2015; Duncan, 1992). The grief of the physical loss of their family member (Butcher *et al.*, 2001) was further exacerbated by a sense of losing the person due to the effects of the dementia on their personality and behaviour (Crawford *et al.*, 2015), and their relationship (Armstrong, 1999). Grief was expressed openly by carers in Tilse’s (1998) study, many crying during the interviews as they recounted their stories.

People with dementia who recalled negative experiences of the move to the care home stated that they missed their independence and being with their close family members (Thein *et al.*, 2011). Some residents said they had not been involved in the decision to move, and resented the secrecy and decisions being made for them (Thein *et al.*, 2011).

Positive emotions

Positive emotions were also experienced by many carers after the move, as they expressed their relief that the person with dementia was now safe, and realisation of the reduction of stress (Butcher *et al.*, 2001; Duncan, 1992; Pierre-Louis, 2012; Tilse, 1998). This was explained as a personal reorganisation, which meant that the carer could experience freedom and enjoy a quiet and relaxed atmosphere (Duncan, 1992). For people with dementia, importance was placed on being able “to start a new life”, and being accepted by others in the care home (Thein *et al.*, 2011, p. 13). Carers seemed more able to relinquish the need for caring if they could see that the person with dementia was being cared for well in the care home (Mistic, 2008; Strang *et al.*, 2006).

IS THERE AN OPTIMAL TIME?

Evidence on the timing of the move to a care home is very limited, and papers in the review referred to it by stating: 'when the time comes' or when the time was 'right', without explaining when exactly this might be (Armstrong, 1999; Caldwell *et al.*, 2014; Duncan, 1992; Tilse, 1998). The 'right time' was seen as being intuitive and subjective (Mamier and Winslow, 2014). One social worker perspective was that there is no "*right or wrong time*", but that it is about the carer's 'readiness', and that "*the 'appropriate time for placement' is subjective, that is 'when one's personal level [limit] of stress and caregiving is reached'*" (Mamier and Winslow, 2014, p. 16). Similarly, Caldwell and colleagues found that the time for a move was reached when both the carer and the person with dementia realised that they were no longer coping with care at home and they felt "*'ready' to accept a place*" (Caldwell *et al.*, 2014, p. 421). The 'readiness' of carers (p. 16) and their ability to cope with increasing care needs (p. 13) have already been described in this paper, and appear to be crucial components when discussing the 'timing' of the move to a care home.

Armstrong found that the timing of many moves occurred just before the Christmas period (Armstrong, 1999) although this was not commented upon by others. This was viewed as a particularly stressful time of the year and "*the straw that broke the camel's back*" (Armstrong, 1999, p. 36), as there would be a lack of support around this holiday time.

However, as noted above, deciding when is the right time for a family member with dementia to move to a care home may be a cause for disagreement amongst other family members (Chang *et al.*, 2011).

DISCUSSION

One of the key findings from this review was the cyclical nature of the decision-making process, with carers constantly re-evaluating when might be the time to make the move. This conceptualises the care move as one of transition or "*as a continuum before and after admission*" (Ashton *et al.*, 2016, p. 23), because relocation "*is not a time-limited event, but an on-going process of adjustment*" (Aminzadeh *et al.*, 2009, p. 494). As the "*decision-making*

process continues over time” (Caron *et al.*, 2006, p. 199), people with dementia and family carers experienced a range of emotions, which revealed the transition from home to a care home to often be an intensely emotional experience for all of those involved in the decision. The range of emotions, being both negative (e.g. guilt, loneliness, shame) and positive (e.g. relief) have been described.

The transitional phases experienced by carers making a decision about a care home move for a person with dementia were described in many of the included papers. They identify stages that highlighted carers’ growing recognition of their need for extra support, their evaluation of other options of care, choosing a care home, relinquishing care at home, and coming to accept their role as a visitor to the care home. These phases are reflected in this review, as the main themes share a temporal element, moving through the decision-making process over time. The emotions of carers and people with dementia strongly influenced the decision-making process, which prevailed through all stages of transitioning from home to a care home. Included in this was the ‘readiness’ of carers and people with dementia to make the move. This appears to be a significant factor in the transitioning period. However, what constitutes an individual being ‘ready’ and how readiness is measured is not known, and this requires further investigation.

The review also identified the need to consider the social and cultural context of expectations around family care. In societies where there is stigma about care home use, the timing of a move may be affected by the risks of stigma and feelings of guilt and ostracism from the wider society or even family. Societal perspectives of care homes may also affect the timing of a move, with evidence that the persistence of a care home being a ‘last resort’ may impact on wishes to stay at home for as long as possible (pull factor) and a wish to avoid moves to a setting that may be neglectful or abusive (push factor).

The financial support available to carers and people with dementia considering a move to a care home varies across countries. However, some sort of financial assistance from the government is available to low-income individuals in all the countries covered by this review. Consequently, decision-making based on the cost of long term care may be more pertinent

to middle- and upper-income individuals, as they are more likely to pay for the care that is provided and may have more to lose in terms of future inheritances.

Limitations

The review was limited by including only English language papers, which may have accounted for the dominance of Western, high-income country studies within the review and additional cultures' studies being overlooked. However, four studies focused on participants from specific cultural and ethnic backgrounds; Chinese [Caldwell, et al. 2014; Chang and Schneider, 2010; Chang et al, 2011], Korean (Park et al, 2004); and African-American (Pierre-Louis, 2012). Twelve studies recorded no information on the ethnicity of their participants. Two additional restrictions were imposed by the review's methodology. The first was the exclusion of the term 'assisted living facilities' from the search. This decision was made due to the wide heterogeneity in services defined as assisted living facilities internationally. The limitations of this are that we may have missed some studies; however, our checking of references and citations did not reveal fresh papers for inclusion. The second was to include only qualitative studies. Justification for this decision was to include rich, detailed data about the experiences of those involved in the decision-making process. However, it is acknowledged that some mixed-method studies may have been beneficial to this review had their qualitative data been more easily distinguishable within the paper. The relevance of some of the studies may be brought into question, due to four studies being published in the last century (Armstrong, 1999; Cahill, 1997; Duncan, 1992; Tilse, 1998). Consequently, it could be argued that these studies may not reflect contemporary views and experiences of care homes. In addition, the QualSyst scale (Kmet *et al.*, 2004) used to establish the quality of papers that met the inclusion criteria had its limitations, as it was often difficult to identify the correct score for the papers on each item on the scale. However, despite these limitations, the review was able to identify several high quality studies that captured a range of experiences, as discussed above.

Gaps in current literature

The studies included in this review provided a 'snap-shot', of the decision-making process. Three studies explored experiences of carers (Armstrong, 1999; Duncan, 1992; Strang *et al.*, 2006) and of people with dementia (Thein *et al.*, 2011) over time. However, there was no real

chronology of the person with dementia's situation or caring relationship. Although studies gained rich data from face-to-face interviews (and focus groups), none of the studies in the review used triangulation techniques to support their findings. Using additional methods to throw light on social contexts, such as the use of genograms, network mapping tools or eco-grams to show the level of support and social interactions of those living with dementia at home, may prove useful to those conducting future research in this area.

Finally, the majority of the views and experiences documented in this review were from the carer perspective. Although there was some input from people with dementia, generally their presence in the research process was under-represented. The general omission of people with dementia from the research may in part be due to many being unable to relate their experiences due to the level of their cognitive impairment and other communication difficulties. However, two papers had sought to gather the views of the people who were moving. Surprisingly, only one paper captured the perspectives of professionals, and this was a single case study, therefore any generalisations from this account should be made with caution. While there is a gap in the evidence to gain the perspective of people with dementia about the timing of this important decision and transition, the views of care home managers, care home staff and other dementia care practitioners are also not represented in this body of work. Future research should consider gaining the perspectives of these important influencers or decision makers.

Future Research

Future research should consider the perspective of all parties and influencers in the decision-making process and the timing of the possible move of person with dementia to a care home, namely the person with dementia, the family carer, care home manager, care home staff and other practitioners. Only when all of these perspectives have been gained will we be able to better understand the intricate interpersonal dynamics and emotional impact of the decision-making process for all involved and what (if any) is an optimal time to move to a care home.

Conflict of Interest

None.

Description of authors' roles

The research question was initiated by KS and JM. LC and KS designed the study and LC carried out the search, selected the papers, conducted the data extraction and drafted the paper. Quality checks were undertaken by KS and LC. Thematic analysis was initiated by LC and verified by KS; with any discrepancies being verified by JM. All authors contributed to the drafting of the paper and agreed on the final paper for publication.

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REFERENCES

Alzheimer's Society. (2013a). *Outcomes of the James Lind Alliance Dementia Priority Setting Partnership*. London: Alzheimer's Society.

Alzheimer's Society. (2013b) *Low Expectations: Attitudes on choice, care and community for people with dementia in care homes*. London: Alzheimer's Society.

Aminzadeh, F., Dalziel, W. B., Molnar, F. J. and Garcia, L. J. (2009). Symbolic meaning of relocation to a residential care facility for persons with dementia. *Aging and Mental Health*, 13(3), 487-496.

doi: 10.1080/13607860802607314

Armstrong, M. (1999). Factors affecting the decision to place a relative with dementia into residential care. *Nursing Standard*, 14(16), 33-37.

Ashton, S., Roe, B. and Jack, B. (2016). Choosing a care home: families need more support. *Journal of Dementia Care*, 24(4), 22-24.

Butcher, H. K., Holkup, P. A., Park, M. and Maas, M. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Research in Nursing and Health*, 24(6), 470-480.

Cahill, S. M. (1997). 'I often think I wish he were here'. Why do primary carers institutionalise their family member with dementia? *Australian Social Work*, 50(3), 13-19.

Caldwell, L., Low, L. F. and Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *International Psychogeriatrics*, 26(3), 413-424.

doi: 10.1017/S1041610213002020

Caron, C. D., Ducharme, F. and Griffith, J. (2006). Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Canadian Journal on Aging*, 25(2), 193-205.

Chang, Y.P. and Schneider, J. K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in Psychiatric Care*, 46(2), 108-118 111p.
doi: 10.1111/j.1744-6163.2010.00246.x

Chang, Y.P., Schneider, J. K. and Sessanna, L. (2011). Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *Journal of Aging Studies*, 25, 436-444.
doi:10.1016/j.jaging.2011.05.001

Chene, B. (2006). Dementia and residential placement: A View from the carers' perspective. *Qualitative Social Work*, 5(2), 187-215.
doi: 10.1177/1473325006064257

(The) Commission on Residential Care. (2014). "A vision for care fit for the twenty-first century..." London: DEMOS.

Crawford, K., Digby, R., Bloomer, M., Tan, H. and Williams, A. (2015). Transitioning from caregiver to visitor in a long-term care facility: the experience of caregivers of people with dementia. *Aging and Mental Health*, 19(8), 739-746.
doi: 10.1080/13607863.2014.962008

Duncan, M. T. (1992). *Alzheimer's Disease Caregivers: The transition from home care to formal care*. Dissertations and Theses. Paper 3228. Portland State University Dissertations and theses.

http://pdxscholar.library.pdx.edu/cgi/viewcontent.cgi?article=4238&context=open_access_etds

Elliott, B. A., Gessert, C. E. and Peden-McAlpine, C. (2007). Decision-making on behalf of elders with advanced cognitive impairment. *Alzheimer's Disease and Associated Disorders*, 21(1), 49-54.

Elliott, B. A., Gessert, C. E. and Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: narrative and ethics. *Scandinavian Journal of Caring Sciences*, 23(2), 251-258.

doi: 10.1111/j.1471-6712.2008.00613.x.

Hagen, B. (2001). Nursing home placement. Factors affecting caregivers' decisions to place family members with dementia. *Journal of Gerontological Nursing*, 27 (2), 44-53.

Joanna Briggs Institute. (2011). *Joanna Briggs Institute Reviewers' Manual: 2011 Edition*. Adelaide: The Joanna Briggs Institute.

Kmet, L. M., Lee, R. C. and Cook, L. S. (2004). *Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields*. Alberta: Alberta Heritage Foundation for Medical Research.

Lord, K., Livingston, G., Robertson, S. and Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. *BMC Geriatrics*, 16:68.

doi: 10.1186/s12877-016-0242-1

Mamier, I. and Winslow, B. W. (2014). Divergent views of placement decision-making: A qualitative case study. *Issues in Mental Health Nursing*, 35(1), 13-20.

doi: 10.3109/01612840.2013.834014

Mistic, M. L. (2008). *"Coming to terms": a grounded theory of dementia caregivers' journeys and expectations of care*. (Ph.D.), The University of Texas Medical Branch Graduate School of Biomedical Sciences. Retrieved from

<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=109851495&site=ehost-live>

Moher, D, Liberati, A, Tetzlaff, J, Altman, DG, and The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med*, 6(7): e1000097.

Orellana, K., Manthorpe, J., and Moriarty, J. (2017). What do we know about care home managers? Findings of a scoping review. *Health & Social Care in the Community*, 25: 366-377.

doi:10.1111/hsc.12313

Park, M., Butcher, H. K. and Maas, M. L. (2004). A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Research in Nursing and Health*, 27(5), 345-356.

doi: 10.1002/nur.20031

Pierre-Louis, M. (2012). *Decision-making process of African Americans caring for parents with Alzheimer's*. Dissertations and theses. John F. Kennedy University, California.

Sandberg, J., Lundh, U., and Nolan, M.R. (2001). Placing a spouse in a care home: the importance of keeping. *Journal of Clinical Nursing*, 10, 406-416.

Sanford, A. M. et al. (2015). An international definition for "nursing home". *JAMDA*, 6, 181-184.

Strang, V. R., Koop, P. M., Dupuis-Blanchard, S., Nordstrom, M. and Thompson, B. (2006). Family caregivers and transition to long-term care. *Clinical Nursing Research*, 15(1), 27-45.

doi: 10.1177/1054773805282356

Thein, N. W., D'Souza, G. and Sheehan, B. (2011). Expectations and experience of moving to a care home: Perceptions of older people with dementia. *Dementia*, 10(1), 7-18.

doi: 10.1177/1471301210392971

Tilse, C. (1998). Continuing or refusing to care: The meaning of placing a spouse in long term care. *American Journal of Alzheimer's Disease*, Jan/Feb, 29-33.

Table 1: Examples of search terms used

Dementia OR Alzheimer's disease OR cognitive impairment
AND move OR transition OR relocate*
AND care home OR residential care OR nursing home OR long term care
AND decision making OR decid* OR decision

Table 2: Inclusion criteria

Date:	Up to the end of December 2016
Types of studies:	All empirical qualitative studies
Language:	In the English language
Context:	Moving from home to a care home
Outcomes:	Experiences of people with dementia, their family carers, professionals

Table 3. Assessment of the quality of qualitative papers using QualSyst (Kmet *et al.*, 2004)

Study	Question	Design	Context	Theoretical framework	Sampling	Data collection	Analysis	Credibility	Conclusion	Reflexivity	Total	Percentage
Aminzadeh <i>et al.</i> (2009)	2	2	2	1	1	2	2	2	2	1	17	85%
Armstrong (1999)	2	2	1	1	1	2	1	2	2	2	16	80%
Ashton <i>et al.</i> (2016)	2	2	2	1	1	1	0	0	2	1	12	60%
Butcher <i>et al.</i> (2001)	2	2	2	1	2	2	2	2	2	1	18	90%
Cahill (1997)	2	2	2	1	2	2	1	1	2	0	15	75%
Caldwell <i>et al.</i> (2014)	2	2	2	1	2	2	2	1	2	1	17	85%
Caron <i>et al.</i> (2006)	2	2	2	1	2	2	2	2	2	1	18	90%
Chang & Schneider (2010)	2	2	1	1	2	2	2	0	2	2	16	80%
Chang <i>et al.</i> (2011)	2	2	2	1	2	2	1	2	2	0	16	80%
Chene (2006)	2	2	2	2	2	2	1	1	2	0	16	80%
Crawford <i>et al.</i> (2015)	2	2	2	1	2	2	1	2	2	1	17	85%
Duncan (1992)	2	2	2	2	2	2	2	2	2	2	20	100%
Hagen (2001)	2	2	1	1	2	2	2	2	2	0	16	80%
Lord <i>et al.</i> (2016)	2	2	2	1	2	2	1	2	2	1	17	85%
Mamier & Winslow (2014)	2	2	1	1	1	1	1	1	2	1	13	65%
Mistic (2008)	2	2	2	2	2	2	2	2	2	0	18	90%
Park <i>et al.</i> (2004)	2	2	2	1	2	2	2	2	2	0	17	85%
Pierre Louis (2012)	1	2	2	2	1	2	1	2	2	2	18	90%
Strang <i>et al.</i> (2006)	2	2	2	1	2	2	2	2	2	1	18	90%
Thein <i>et al.</i> (2011)	2	2	2	1	1	2	1	2	2	1	16	80%
Tilse (1998)	2	2	2	1	2	2	2	0	1	0	14	70%

Table 4. Methodological characteristics, findings, quality ratings of included qualitative papers.

*CH = care home.

	Study	Country	Qualitative Methods Used	Prospective or retrospective of CH move	Study Participants	Number of participants	Findings	Quality
1	Aminzadeh <i>et al.</i> (2009)	Canada	In-depth interviews	Prospective	People with dementia	16	Symbolic meaning of relocation to a CH	Good
2	Armstrong (1999)	UK	Semi-structured interviews (x2)	Prospective & retrospective	Carers	4	Factors affecting the decision to move to a CH	Good
3	Ashton <i>et al.</i> (2016)	UK	Semi-structured interviews	Retrospective	Carers	12	Trigger – considering CH. Choosing a CH	Adequate
4	Butcher <i>et al.</i> (2001)	US	Semi-structured interviews	Retrospective	Carers	30	The decision-making experience to move to a CH	Good
5	Cahill (1997)	Australia	In-depth interviews	Retrospective	Carers	39	The decision-making experience to move to a CH	Good
6	Caldwell <i>et al.</i> (2014)	Australia	Semi-structured interviews	Prospective or retrospective	Carers	27	The decision-making experience to move to a CH	Good
7	Caron <i>et al.</i> (2006)	Canada	In-depth interviews	Retrospective	Carers	14	The decision-making process to move to a CH	Good
8-9	Chang and Schneider (2010); Chang <i>et al.</i> (2011)	Taiwan	Semi-structured interviews	Prospective or retrospective	Carers	30	The decision-making process to move to a CH	Good
10	Chene (2006)	Australia	Interviews	Prospective or retrospective	Carers	20	The decision-making process to move to a CH	Good
11	Crawford <i>et al.</i> (2015)	Australia	Semi-structured interviews	Prospective	Carers	20	Experience of a person with dementia moving to a CH	Good
12	Duncan (1992)	US	Focus groups	Prospective & retrospective	Carers	179	Deciding to move to a CH and the transition process	Good
13	Hagen (2001)	Canada	In-depth interviews Interviews	Retrospective Prospective	Carers	10 5	The decision-making process to move to a CH	Good
14	Lord <i>et al.</i> (2016)	UK	Semi-structured interviews	Prospective or retrospective	People with dementia Carers	7 13	The decision-making process to move to a CH. Developing a decision aid	Good

15	Mamier and Winslow (2014)	US	Semi-structured interviews	Prospective &/ or retrospective	Carer Professional	1 1	Perspectives on decision-making on move to CH	Adequate
16	Mistic (2008)	US	Semi-structured interviews	Prospective or Retrospective	Carers	13	Transitions (stages) to a person with dementia moving to a CH	Good
17	Park <i>et al.</i> (2004)	Korea	Semi-structured interviews	Retrospective	Carers	19	Experience of deciding to move to a CH	Good
18	Pierre Louis (2012)	US	Semi-structured interviews	Retrospective	Carers	6	The decision-making process to move to a CH	Good
19	Strang <i>et al.</i> (2006)	Canada	Repeated open-ended interviews	Prospective & retrospective	Carers	29	Experience of being on a CH waiting list and the transition process	Good
20	Thein <i>et al.</i> (2011)	UK	Semi-structured interviews (x2)	Prospective & retrospective	People with dementia	18	Experience of moving to a CH: before and after	Good
21	Tilse (1998)	Australia	In-depth interviews	Retrospective	Carers	18	Meaning of a person with dementia moving to a CH	Good

Table 5: Table of people with dementia and carers' characteristics

Study	Person with dementia					Carer				Professional	
	Gender	Age range (mean) in years	Ethnicity	Type /stage of dementia	PWD moving from...? (place) PWD lived /with?	Gender	Age range (mean) in years	Ethnicity	Relationship to PWD	Duration of caring (mean) in years	Age (in years), Gender, Ethnicity
Aminzadeh <i>et al.</i> (2009)	F-11 M-5	76-95 (85.3)	Place of birth: Canada-12 Europe-3 Asia-1	AD-4 VaD-3 Mixed-5 Unspecified-4 Mild-11 Moderate-3	Home Alone-11 Spouse/partner-4 Boarder-1	-	-	-	-	-	-
Armstrong (1999)	-	-	-	-	Home Alone-11 Carer -3	F-4 M - 0	-	-	Spouse-2 Adult-child-2	1-10	-
Ashton <i>et al.</i> (2016)	-	-	-	Type/s unspecified Advanced dementia, end of life	Home Carer-6 PWD did not live with Carer-14	F-8 M-4	-	-	Spouse-4 Adult-child-4 Sibling-1 Grand-child-1 Niece/nephew-2	-	-
Butcher <i>et al.</i> (2001)	-	-	-	Type/s unspecified Moderate to severe dementia	Home	F-24 M-6	18+	African American-7 White non-Hispanic-20 Native American-3	Spouse-9 Adult-child-21	-	-
Cahill (1997)	-	-	-	"Dementing disorder" (p.14)	Home to hospital Carer -35 PWD did not live with Carer-4	F-39 M-0	35-85 (spouse-70 Non-spouse-54)	-	Spouse-24 Adult-child-12 Other (unspecified)-3	-	-
Caldwell <i>et al.</i> (2014)	-	-	Chinese background -20 English speaking background-7	-	Home Carer -11 PWD did not live with Carer-16	F-19 M-8	33-86 (58)	Chinese Background-20 English speaking background-9	Spouse-22 Adult-child-3 Niece/nephew-2	-	-
Caron <i>et al.</i> (2006)	F-4 M-4	60-over 90		Type/s unspecified		F-10 M-4	40-over 70	-	Spouse-2 Adult-child-11	-	-

Onset of cognitive loss:										Sibling-1		
Chang & Schneider (2010); Chang <i>et al.</i> (2011)	F-14 M-16	-	-	-	AD-23 VaD-6 Unspecified-1 Very mild-1 Mild-6 Moderate-10 Severe-13		F-19 M-11	25-83 (49.3)	Chinese-30	Spouse-5 Adult-child-21 Grand-child-2 Niece/nephew-2	1-8 (3.2)	-
Chene (2006)	-	65 and older	-	-	"Primary diagnosis of dementia" (p. 194)	Home Alone-9 Carer -11	F-15 M-5	(64)	-	Spouse-9 Adult-child-9 Sibling-1 Niece/nephew-1	>1 and <10	-
Crawford <i>et al.</i> (2015)	-	-	-	-	-	Home Carer-16 PWD did not live with carer-4	F-11 M-9	34-92	-	Spouse-14 Adult-child-4 Friend-2	-	-
Duncan (1992) Focus groups	-	-	-	-	-	Home Carer -77 PWD did not live with carer-102	-	-	-	Spouse-78 Adult-child-103	-	-
Interviews	-	-	-	-	-	Home	F-7 M-5	-	-	Spouse-6 Adult-child-6	-	-
Hagen (2001)	-	65+	-	-	-	Home Carer-5	F-4 M-1	34-72	-	Spouse-2 Adult-child-3	-	-
Lord <i>et al.</i> (2016)	F-2 M-5	71-87 (79)	White British-6 Asian-1	-	Clinical diagnosis of dementia	Home Alone-2 Partner-1 Other relative-3 Care home-1	F-9 M-4	32-85 (59)	White British-11 Asian-2	Spouse-5 Adult-child-7 Niece/nephew-1	-	-

Mamier and Winslow (2014)	M-1	-	-	AD	Home Carer-1	F-1	Late 70's	-	Spouse-1	7	Age: Mid 40's Gender: female Ethnicity: unknown
Mistic (2008)	F-6 M-7	62-89 (78)	-	"Diagnosis of dementia" (p.58) Time since dementia diagnosis: 1.5-6.5 years (37 months)		F-9 M-4	40-78	African American-2 Caucasian-8 Hispanic-2 Asian-American-1	Spouse-5 Adult-child-7 Cousin-1	0.5 - 5 (32 months)	-
Park <i>et al.</i> (2004)	F-16 M-3	60-91 (73.21)	-	-	Home Alone-5 Carer-14	F-11 M-8	36-65 (50.37)	Korean-19	Spouse-2 Adult-child-14 Sibling-2 Niece/nephew-1	1-10	
Pierre Louis (2012)	F-5 M-1	-	-	AD Diagnosis min. of 2 years.	Home Carer-6	F-6 M-0	43-69	African American-6	Adult-child-5 Grand-child-1	1-8 (4)	-
Strang <i>et al.</i> (2006)	-	-	-	-	Assumed - home	F-22 M-7	26-88 (60.4)	-	Spouse-8 Adult-child-18 Other (unspecified)-2	1-17	-
Thein <i>et al.</i> (2011)	F-11 M-7	65+	-	-	Home	-	-	-	-	-	-
Tilse (1998)	-	-	-	AD	Not known	-	-	-	Spouse-15	-	-

KEY:	
-	No information provided
AD	Alzheimer's disease
F	Female
M	Male
PWD	Personal with dementia
VaD	Vascular dementia

Table 6: Summary of themes

1. WHAT HAPPENED BEFORE THE MOVE?
Butcher <i>et al.</i> , 2001; Caron <i>et al.</i> , 2006; Crawford <i>et al.</i> , 2015; Lord <i>et al.</i> , 2016
Crisis event
Ashton <i>et al.</i> , 2016; Butcher <i>et al.</i> , 2001; Cahill, 1997; Caldwell <i>et al.</i> , 2014; Caron <i>et al.</i> , 2006; Chene, 2006; Crawford <i>et al.</i> , 2015; Duncan, 1992; Mamier and Winslow, 2014; Strang <i>et al.</i> , 2006
Worsening symptoms of dementia or general health of person with dementia
Aminzadeh <i>et al.</i> , 2009; Armstrong, 1999; Butcher <i>et al.</i> , 2001; Cahill, 1997; Caldwell <i>et al.</i> , 2014; Caron <i>et al.</i> , 2006; Chang and Schneider, 2010; Crawford <i>et al.</i> , 2015; Duncan, 1992; Lord <i>et al.</i> , 2016; Mamier and Winslow, 2014; Mistic, 2008; Park <i>et al.</i> , 2004; Thein <i>et al.</i> , 2011
Carer recognition of being unable to cope
Armstrong, 1999; Ashton <i>et al.</i> , 2016; Butcher <i>et al.</i> , 2001; Cahill, 1997; Caldwell <i>et al.</i> , 2014; Caron <i>et al.</i> , 2006; Chang and Schneider, 2010; Chene, 2006; Crawford <i>et al.</i> , 2015; Duncan, 1992; Lord <i>et al.</i> , 2016; Mistic, 2008; Mamier and Winslow, 2014; Park <i>et al.</i> , 2004; Pierre-Louis, 2012; Strang <i>et al.</i> , 2006; Tilse, 1998
2. PLANNING FOR THE MOVE
Available alternatives
Caldwell <i>et al.</i> , 2014; Caron <i>et al.</i> , 2006; Duncan, 1992; Lord <i>et al.</i> , 2016; Mamier and Winslow, 2014; Park <i>et al.</i> , 2004; Pierre-Louis, 2012
Waiting list option
Cahill, 1997; Caldwell <i>et al.</i> , 2014; Duncan, 1992; Strang <i>et al.</i> , 2006
Carer readiness to make the decision
Butcher <i>et al.</i> , 2001; Caldwell <i>et al.</i> , 2014; Duncan, 1992; Hagen, 2001; Mamier and Winslow, 2014; Park <i>et al.</i> , 2004; Strang <i>et al.</i> , 2006
3. WEIGHING UP THE DECISION
Caron <i>et al.</i> , 2006; Mamier and Winslow, 2014
Finances
Chang and Schneider, 2010; Chang, <i>et al.</i> , 2011; Duncan, 1992; Lord <i>et al.</i> , 2016; Mamier and Winslow, 2014; Park <i>et al.</i> , 2004
A care home move is considered a last resort

Caldwell *et al.*, 2014; Chang *et al.*, 2011; Chene, 2006; Duncan, 1992; Hagen, 2001; Lord *et al.*, 2016

4. LACK OF SUPPORT

Lord *et al.*, 2016

Peer and professional support

Armstrong, 1999; Ashton *et al.*, 2016; Butcher *et al.*, 2001; Caron *et al.*, 2006; Chang and Schneider, 2010; Chang *et al.*, 2011; Duncan, 1992; Hagen, 2001; Lord *et al.*, 2016; Mamier and Winslow, 2014; Park *et al.*, 2004

Inadequate services

Armstrong, 1999; Caron *et al.*, 2006

Choosing the right care home

Ashton *et al.*, 2016; Butcher *et al.*, 2001, Cahill, 1997; Caldwell *et al.*, 2014; Chang *et al.*, 2011; Crawford *et al.*, 2015; Duncan, 1992; Lord *et al.*, 2016; Mamier and Winslow, 2014; Mistic, 2008; Park *et al.*, 2004

5. DRIVERS OF THE DECISION

Family negotiations – decision maker roles

Ashton *et al.*, 2016; Butcher *et al.*, 2001; Cahill, 1997; Caldwell *et al.*, 2014; Caron *et al.*, 2006; Chang and Schneider, 2010; Chang *et al.*, 2011; Chene, 2006; Duncan, 1992; Hagen, 2001; Lord *et al.*, 2016; Mistic, 2008; Park *et al.*, 2004; Strang *et al.*, 2006; Tilse, 1998

Person with dementia and decision-making

Caldwell *et al.*, 2014; Caron *et al.*, 2006; Chang *et al.*, 2011; Chene, 2006; Duncan, 1992; Lord *et al.*, 2016; Strang *et al.*, 2006; Thein *et al.*, 2011

6. EMOTIONAL SIGNIFICANCE OF THE MOVE

Aminzadeh *et al.*, 2009; Butcher *et al.*, 2001; Caldwell *et al.*, 2014; Chang and Schneider, 2010; Chang *et al.*, 2011; Crawford *et al.*, 2015; Hagen, 2001; Mamier and Winslow, 2014; Thein *et al.*, 2011; Tilse, 1998

7. CONTINUED REFLECTION ON THE DECISION

Continuation of the caring and kin-relationship

Ashton *et al.*, 2016; Butcher *et al.*, 2001; Caldwell *et al.*, 2014; Chang and Schneider, 2010; Chang *et al.*, 2011; Crawford *et al.*, 2015; Duncan, 1992; Mamier and Winslow, 2014; Pierre-Louis, 2012; Strang *et al.*, 2006; Thein *et al.*, 2011; Tilse, 1998

Emotional responses following the move

Armstrong, 1999; Butcher *et al.*, 2001; Caldwell *et al.*, 2014; Caron *et al.*, 2006; Chang and Schneider, 2010; Chang *et al.*, 2011; Duncan, 1992; Mistic, 2008; Park *et al.*, 2004; Pierre-Louis, 2012; Strang *et al.*, 2006

Loss and grief

Armstrong, 1999; Butcher *et al.*, 2001; Crawford *et al.*, 2015; Duncan, 1992; Thein *et al.*, 2011; Tilse, 1998

Positive emotions

Butcher *et al.*, 2001; Duncan, 1992; Mistic, 2008; Pierre-Louis, 2012; Thein *et al.*, 2011; Strang *et al.*, 2006; Tilse, 1998

8. IS THERE AN OPTIMAL TIME?

Armstrong, 1999; Caldwell *et al.*, 2014; Chang *et al.*, 2011; Duncan, 1992; Mamier and Winslow, 2014; Tilse, 1998

Figure 1: PRISMA flow diagram: search and selection procedure (Moher *et al.*, 2009)