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REVIEW ARTICLE

Involvement of older adults in shared decision-making on care transitions in the UK: an interpretative qualitative systematic review

Lucia Halamová[1,2], Louise Locock[2], Andrew Maclaren[2], Stephen Makin[2] and Louise Phillips[1]

[1]Department of Psychology, University of Aberdeen, Aberdeen, UK and [2]Aberdeen Centre for Evaluation (formerly Health Services Research Unit), The Institute of Applied Health Sciences, University of Aberdeen, Aberdeen, UK
Corresponding author: Lucia Halamová; Email: l.halamova.23@abdn.ac.uk

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Abstract

The global population is ageing rapidly, emphasising the need to understand the decision-making processes of older adults regarding potential care transitions. Gerontological research has focused on healthcare decisions, with less information on living situation choices of older adults. This review explored older adults' experiences with their involvement in decision-making processes related to transitioning into care facilities in the United Kingdom. From a systematic search of articles, nine were reviewed using thematic narrative synthesis. Four themes with nine subthemes were identified: *Involvement in decision-making* (Exclusion of older adults, Usefulness of involvement), *The necessity of moving* (Triggers for moves, The role of family), *Timely planning* (Helpfulness of planning, Planning avoidance), and *Factors for choosing a care home* (Non-quality factors, Quality factors, Continuity of life). These themes highlighted the issue of inadequate involvement of older adults in decision-making, often resulting in negative consequences like regret and difficulty settling into new care settings. *The necessity of moving* arose from sudden events or increased support needs. Some older adults acknowledged the necessity due to declining health or to spare family burden, while relatives grappled emotionally, postponing the choice. *Timely planning* was found to be beneficial practically and emotionally, facilitating smoother transitions. However, participants would rarely plan and discuss such matters early. Older adults focused on personal experiences and trusted sources rather than publicly available information when considering *Factors for choosing a care home*. The findings show the need for greater inclusion of older adults in decisions related to their care and the importance of early planning and providing preferred types and formats of information to aid decisions. Future research should focus on a better understanding of older adults' preferences for successful involvement in care decisions, with support and guidance for others involved in the decisions.

Keywords: ageing; care facilities; care homes; decision-making; interpretative qualitative systematic review; older adults; thematic narrative synthesis; transition

Introduction

With the ageing population increasing globally (United Nations 2019) and locally in the UK (Centre for Ageing Better 2023), there is an increasing demand for care for older adults (Skills for Care 2023a). In the UK, this may vary from 'home help' providing day-to-day domestic assistance without personal care (NHS 2024) to sheltered housing, where older adults live in housing complexes with easier access to care (NHS 2021), to 24-hour staffed care homes. There are two main generally recognised types of care home in the UK: residential homes, offering support with personal care, such as washing, dressing and using the toilet; and nursing homes, offering support to people with greater medical needs, with on-site nurses (Burton et al. 2019; NHS 2022). Despite these options, reports from England indicate that job vacancies in these sectors have been increasing since 2016, with higher vacancy rates in 'home help' services (Skills for Care 2023b) compared to care and nursing home staffing (Skills for Care 2023c, 2023d). Additionally, while recognising that a care home placement may not be the most desirable option for all older adults, Alzheimer Scotland (2024) reports that the current system fails to offer adequate alternatives for long-term care. In this review, transitions into care will be explored, adopting Burton and colleagues' (2022, e186) definition of care homes, which includes a variety of available caring facilities defined as '24-hour residential care settings providing care and support for older adults (aged ≥ 65 years) both with and without on-site registered nursing staff'.

Moving to a care home can be particularly distressing and emotional for older adults. Physically, even voluntary transition was shown to increase older adults' cortisol levels, indicating increased stress responses (Hodgson et al. 2004). Mentally, they often suffer worsened wellbeing through feelings of loss – from abstract concepts such as losing freedom and autonomy, through material losses of house and belongings, to social losses of family and friend contact (Lee et al. 2002; Nay 1995; Richards 2011). These negative outcomes for mental wellbeing (including sadness, loneliness, anxiety and others) can be amplified and/or prolonged if the older adults feel a lack of involvement and control in the decision-making process and transition, as well as if there is a lack of support from professionals pre- and post-transition, especially in relation to psychological, social and emotional aspects of the transition (Groenvynck et al. 2022; Lee et al. 2002; Sury et al. 2013; Tanner et al. 2015; Wilson 1997).

This suggests that shared decision-making (SDM) would be helpful for a smoother transition for older adults. Rooted in clinical models, SDM integrates both the clinician's expertise and the patient's self-knowledge. While the clinician provides detailed, comprehensive information about the condition, including the risks and benefits of treatment options, the patient contributes their values, preferences and concerns regarding potential treatments (Elwyn et al. 2012). In the context of transitioning to a care home, SDM would ideally involve the older adult at the centre of the process, with input from a diverse group of stakeholders. These might include spouses, children, extended family, friends or legally appointed guardians/surrogates (Roberto 1999; Sager et al. 2019), as well as social workers, care home staff, managers and medical professionals (Leyland et al. 2016). In practice, however, the decision-making process is often dominated by these other stakeholders, with the older adult's involvement frequently diminished. This may be because older adults tend to be viewed as more passive in decision-making compared to other age groups (Say et al. 2006). Older adults may also relinquish these choices to health-care providers or carers (family members or others) owing to reasons such as a sense of agency loss and feeling overlooked (Bynum et al. 2014), deference to doctors, limited experience in decision involvement, cognitive impairment (Wetzels et al. 2004), difficulty handling numerous options (Reed et al. 2008) and trust in family members (High 1993).

Further exclusions may happen due to a lack of discussions with older adults while they are still able to fully participate. Catalysts for seeking care may be increased physical and cognitive frailty and vulnerability of the older adults (Butcher et al. 2001; Smallegan 1985); for example, 49 per cent of older adults who moved into Scottish care homes had a pre-existing dementia diagnosis (Burton et al. 2019). Another set of catalysts includes mental and physical limits of the primary family care-givers (Mcfall and Miller 1992; Toot et al. 2017) and their eventual inability to offer adequate care to their older relatives (Robinson and Fisher 2024). Such diagnoses or changes mean that families often delay discussing relocation until older relatives can no longer live independently, with hospitalisation instead prompting a move to somewhere with on-site care and the need for new plans (Crawford, 2015; Penrod and Dellasega 1998).

Advance care planning, generally understood as the process of discussions and planning for decision-making at a point in life when a person has lost their decision-making capacity (National Institute on Aging 2022), may be a way to mitigate this lack of involvement at a point of crisis. Typically, advance directives (legal documents that take effect when a person can no longer make their own decisions) as well as non-legally binding decision aids are used in this process. The use of such documents for older adults has been found to be effective in reducing decisional conflict, increasing knowledge on the topic about which a decision is being made, and facilitating better preparedness for decision-making, better understanding of risks and improved patient–provider communication and patient participation (Cardona-Morrell et al. 2017; Fung et al. 2021; Gans et al. 2023; Lord et al. 2017; van Weert et al. 2016).

Despite the potential advantages of decision aids in health care, relatively little is known about their use in care transitions. This is the gap in the evidence which this review seeks to fill. Gans and colleagues' (2023) review and meta-analysis on the effectiveness of decision aids found that the majority of decision aids for older adults were used for health- and medical-intervention-related situations. Likewise, while reviews have covered topics such as the timing of and factors influencing care transitions (Cole et al. 2018; Toot et al. 2017), carer decision-making experiences prior to transition (Lord et al. 2015), and SDM within care (Lynch et al. 2022), little is known about how older adults experience and participate in the decision-making prior to transitions. Toot and colleagues (2017) identified that causes of transition to care homes related to physical, cognitive and mental health difficulties, environmental and service factors and 'care-giver burden', but the review did not capture the direct experiences of either older adults or other stakeholders. Cole and colleagues (2018) reviewed the 'optimal time' for moving a person with dementia to a care home, finding it difficult to define. They identified similar factors for relocation to those of Toot and colleagues' (2017), while primarily featuring carer perspectives. Other reviews, including Lord and colleagues' (2015), focus specifically on the family carers' experience with being involved in care decisions for their older relatives. Lord and colleagues (2015) highlighted the challenges family carers face in making decisions for relatives with dementia, particularly when unable to honour their wishes. A review by Lynch and colleagues (2022) focused on improving older adults' involvement in SDM within care, addressing primarily the period after the transition. The review showed that SDM is typically restricted, and families and residents do not feel adequately supported to be active participants in the process. Overall, the involvement of older adults in decision-making about care transitions is little explored in reviews.

A new contribution of this review is that it focuses on *older adults' experiences as decision-makers* throughout the transition process to care homes while contextualising their involvement within the broader framework that acknowledges the significant role of other stakeholders in the process.

Aims

The first aim of this review was to explore how and to what extent older adults in the UK are involved in the decision-making processes related to their transition to care homes. The secondary aim was to explore consequences of their degree of involvement in decision-making.

Methods

A systematic search was carried out, following the standard processes to assure rigour in including all appropriate studies (Howie 2019; Magarey 2001). This was followed by a thematic narrative synthesis to capture the complexities of the diverse research and the personal experiences of the older adults in these studies (Phoenix et al. 2010).

Systematic search

The databases included in the search were advised by an information specialist. These included two more general databases, Web of Science and Scopus, a health-focused database, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and a social sciences-focused database, ASSIA (Applied Social Sciences Index and Abstracts). The inclusion criteria were set for articles in which the research was carried out within the UK (as this review should inform future work with the application there), with a time span of ten years (May 2014 to May 2023); articles were included if they were peer-reviewed papers of empirical studies. The search terms, listed in Table 1, were developed based on the terms frequently used in the literature following an initial review of the topic. The terms focused on the *transitional nature of changing their care setting* and the *participation in these decisions*, potential *care settings*, such as care homes, nursing facilities or residential care, within the population of *older adults.*

After completing the database search and removing duplicates, forward and backward citation searches were conducted on the included studies. This process was repeated until no new eligible studies were found. Figure 1 shows a PRISMA (Preferred Reporting Items for Systematic Meta Analysis) flow diagram depicting the data extraction process. A total of 1,242 articles were screened in Mendeley Referencing Manager, and 9 articles were identified for synthesis in the review. Given the relatively low number of identified studies, formal quality appraisal was not deemed appropriate.

Table 1. Search terms used in the current systematic search

Order of search	Words and Boolean operators used in the search
Search terms 1	transition* OR transfer* OR move OR moving OR admission OR apply* OR replacement OR entry OR select*
Search terms 2	‘care home’ OR ‘nursing home’ OR ‘nursing facility’ OR ‘care facility’ OR ‘residential care’
Search terms 3	Decision making OR participat* OR involve* OR choice* OR choose*
Search terms 4	‘older adults’ OR elderly OR old* OR ‘older people’

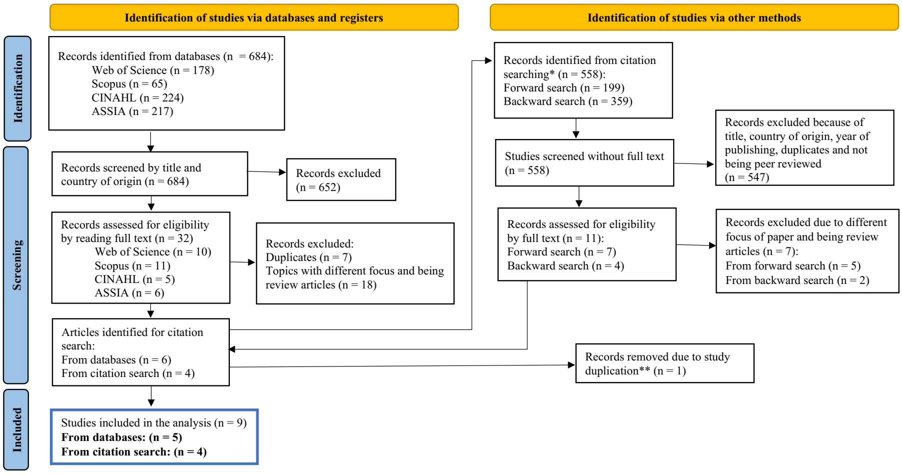

Figure 1. PRISMA flow diagram.
*Forward and backward search was first carried out for six studies identified for citation search from the database search, then for the articles identified from forward and backward citation search.
**One article (Trigg et al. 2018) was removed from the database-found articles because it combined three studies (from three different countries), one of which was found through a citation search and was specifically for England (Kumpunen et al. 2019). Since the article found through citation search was more detailed and focused, it was included over the original one.

Instead, the authors reviewed the studies identified by LH and agreed on the inclusion of all, reporting their shortcomings in *Findings*.

Thematic narrative synthesis

The use of narrative synthesis was informed by Phoenix and colleagues’ (2010) narrative techniques in ageing studies in combination with Popay and colleagues’ (2006) guidance report on narrative synthesis. Preliminary synthesis was adapted from Popay and colleagues’ (2006) report, including *Textual description of studies* and *Tabulation* (describing core information from identified studies and organising them in a table form; see Table 2), and *Translating data through thematic analysis*. Thematic analysis was adapted for narrative synthesis, identifying themes, while following the narrations of individual participants as presented in the studies, based on their own perceived realities as well as context (Pocock et al. 2021). As Phoenix and colleagues (2010) argue, the significance lies not only in what is explicitly stated but also in how it is articulated, as well as in what is omitted or merely implied.

The themes were initially developed by LH, then finalised through iterative discussion with co-authors. The initial process involved familiarisation with the results of the studies, identifying topics relevant to the question of this review within the result sections of the articles on a sentence-by-sentence basis (including the quotes as well as the authors' summary of their findings), and identifying codes. Similar codes were then identified within other studies, with new codes being identified iteratively, using MS OneNote for organization. Once no new codes were identified, LH grouped them into lower-level themes and presented these, along with suggestions for overarching themes, to the supervisory team. Then, LH explained the rationale for each theme, supporting decisions with text excerpts. The supervisory team and LH discussed their appropriateness, suggesting refinements. General agreement was reached, with discrepancies addressed through discussion until consensus was achieved.

The use of the narrative approach helped to interpret the findings from studies and identify themes selected based on the authors' interpretation of older adults' experiences, building on older adults' subjective constructions of their lived experiences (Phoenix et al 2010). Therefore, a statement on author reflexivity is included, to allow for the backgrounds of all collaborating authors involved to be considered when interpreting the themes and presented narrative (Levitt et al. 2018). The lead author, LH, is a postgraduate student with a background in psychology and is the sole author who grew up outside the UK; LH has gained experience supporting lonely and isolated older adults through volunteering activities in the UK. Regarding the other authors: SM is a senior clinical lecturer and consultant geriatrician, LP is a professor in psychology, LL is a professor in health services research and AM is a human geographer and health services researcher. All co-authors have experience conducting research involving older adults.

Findings

Systematic search outcome

The studies identified for the review were all qualitative or mixed-methods studies with qualitative sections described in Table 2. From the mixed-methods studies, only the qualitative components were deemed relevant to the research questions of this review.

Five out of nine studies provided more input from other stakeholders than older adults themselves. Specifically, studies by Leyland and colleagues (2016), Lord and colleagues (2016), Samsi and colleagues (2022), Scheibl and colleagues (2019) and Rhynas and colleagues (2018) predominantly relied on other people's accounts of the older adults' experiences. Even when authors described efforts to mitigate this in their analysis, they provided little insight into the methods used, as direct quotations continued to prioritise the narratives of other stakeholders. The rest of the studies interviewed older adults only. Most studies were socio-demographically homogeneous; only one study (Lord et al. 2016) purposefully recruited a diverse sample. Other studies either provided limited socio-demographic details or indicated that samples were predominantly white.

Table 2. Overview of studies with information with a focus on the current review question

Authors, year	Location	Who was interviewed	Questions answered in the study	Key findings/implications
Kumpunen et al. (2019)	England (London, the South-East and the North of England)	Older adults aged 65–94 (n = 23) who were experienced with social services, prospective care home residents or relatives of care home residents (n = 4)	How do older people with dementia and their family carers make decisions about relocating, what is the decision-making process and what needs and difficulties may need to be overcome? How should a decision aid be designed and administered to help with such decision-making?	Residents' quality of life was found to be the most important quality indicator. Clinical indicators were the least important. Comparing indicators was useful for shortlisting care homes to visit. Participants were concerned about the trustworthiness of available information. Quality information may not be useful if an older person does not have the support to understand it fully.
Leyland et al. (2016)	England (North of England)	Older relocated residents (n = 11), age not noted relatives (n = 2), care home staff (n = 13), managers (n = 6), advocates (n = 2)	How do older adults experience transition to a care home during the immediate pre-placement and post-placement period? How does use of a protocol affect the transition?	There was good adherence to a protocol, ensuring a relatively smooth transition for older adults. Findings highlighted the importance of continuity and consistency, a person-centred approach towards older adults, and social and physical needs to be catered to individually for a smooth transition. The involvement of family members and neutral advocates was seen as helpful. Relocation of previous staff had an impact on older adults' transition. Readjustment issues were mitigated or aggravated based on service delivery. Older adults experienced varied negative emotions related to the forced move, its time management and loss of their old home.

(*Continued*)

Table 2. *(Continued.)*

Authors, year	Location	Who was interviewed	Questions answered in the study	Key findings/implications
Lord et al. (2016)	England (inner and outer London)	Older adults with dementia aged 71–87 ($M_{age} = 79$, $n = 7$), carers ($n = 13$)	What are the processes in place when older adults are moved involuntarily to a different home after their original home had to close? What is the experience of the older adults in this situation?	Most people with dementia felt uninvolved in care decisions, as these were made once their judgement was deemed impaired. Higher-functioning older adults preferred to stay home, and factors that helped them keep independence were valued. Large differences existed among older adults’ wishes. Decision-makers struggled to combine the physical and mental needs of older adults and their wishes. The decision aid was seen as useful but preferably should not be given too soon in the diagnosis process.
O’Neill et al. (2020)	UK (large Health and Social Care trust in the UK)	Older adults directly before or after care home relocation, aged 60–92 ($M_{age} = 82.4$, $n = 23$), one adult under age 65 (aged 60)	What are the perspectives of older adults on the transition to a care home and the life and death within the care home?	Older adults did not feel involved in transitional choices and felt ‘at the mercy’ of others who made the decisions for them. The lack of participation and autonomy had negative emotional effects on older adults. Older adults displayed resigned acceptance after a choice had been made for them. Important for older adults to retain their own identity, having continuity in life and having close people nearby.
Pocock et al. (2021)	England (South-West of England)	Older adults aged 85+ with advanced progressive condition or considered frail ($n = 5$), advanced dementia excluded	What are the decision-making processes for a discharge of older people admitted to a hospital, following a discharge to a care home? What is the involvement of older people in this process?	During the stage of making decisions, as well as living in a care home, older adults felt excluded and experienced a loss of agency and autonomy. Older adults did not have much choice over end-of-life care.

(Continued)

Table 2. (*Continued.*)

Authors, year	Location	Who was interviewed	Questions answered in the study	Key findings/implications
Rhynas et al. (2018)	Scotland	Case records of older adults aged 78–94 ($n = 10$); case records were written by nurses and included perspectives of the older people, family members and professionals	What are the decision-making processes for a discharge of older people admitted to a hospital, following a discharge to a care home? What is the involvement of older people in this process?	The voices of the older adults were often missing from records and decisions were being made for them by family members, carers and health professionals. Patient safety was being put forward by health professionals, even when family members wanted to uphold older adults' wishes.
Samsi et al. (2022)	England (South of England)	Older care home residents with dementia aged 80–89 ($M_{age} = 82.6$, $n = 5$), relatives of older adults with dementia ($n = 21$)	What are the factors that led to the older people's move to a care home? What decision-making roles do the older adults with dementia have in this step? What decision-making roles do carers and care home managers have in this step?	The point at which older adults with dementia started to see they may need to relocate was often after realising their own deterioration and increasing demands on their family carers. Many older adults did not want to relocate, but they gave in. Family carers and professionals led the decision-making process on behalf of older adults.

(*Continued*)

Table 2. (*Continued.*)

Authors, year	Location	Who was interviewed	Questions answered in the study	Key findings/implications
Scheibl et al. (2019)	England (Cambridge)	Older adults from the Cambridge City over 75s cohort aged 95+ ($M_{age} = 97.1$) who relocated ($n = 23$), proxy informants (family members, friends, care home managers) ($n = 29$)	How are 'older old' people involved in assistance seeking and moving to a care home? How are other stakeholders involved in this decision-making?	The majority of 'older old' people were not fully responsible for the decision to move, sharing the decision-making; others were convinced or pushed to relocate by someone. Moving in a time of crisis is traumatising for both older adults and their relatives/carers. Decisions about relocation were usually either suggested, negotiated or pushed by family members.
Stevens et al. (2015)	UK (South of the UK)	Older care home residents with minimal care needs in homes with Registered Nurse care aged 86–99 ($n = 12$)	What are the experiences of older adults with minimal care needs admitted to residential care with 24-hour residential nurse care?	Identified factors precipitating the move: older adult's illness and hospitalisation events; own realisation of need for more care; and family's realisation that they were no longer able to offer adequate care at home. Older adults who were able to make their own decisions about the transition (or were more significantly involved and self-motivated to settle in) found it easier to settle in a care home. Lack of available information about differences in care homes.

Thematic narrative synthesis

The themes identified through thematic narrative synthesis focus on the experiences of older adults while also considering the contextual factors in which these experiences were nested. The main themes and sub-themes identified were:

1. Involvement in decision-making
    1.1 *Exclusion of older adults*
    1.2 *Usefulness of involvement*
2. The necessity of moving
    2.1 *Triggers for moves*
    2.2 *The role of family*
3. Timely planning
    3.1 *Helpfulness of planning*
    3.2 *Planning avoidance*
4. Factors for choosing a care home
    4.1 *Non-quality factors*
    4.2 *Quality factors*
    4.3 *Continuity of life*

1. Involvement in decision-making

This theme explores the nuances regarding the limited involvement of older adults and the extent to which they participate in decision-making. The involvement of older adults in decision-making in care transitions was widely reported as lacking throughout the studies (all except Kumpunen et al. 2019) and was often accompanied by older adults' feelings of frustration, sadness and upset. This exclusion sometimes followed swift decision-making carried out by family for older adults who were no longer considered capable of making those decisions themselves. Where older adults were involved, even in smaller ways, positive experiences and outcomes were reported.

1.1 Exclusion of older adults

The limited participation of older adults in decision-making often came from the beliefs of family members and health professionals that they should be responsible for the older adult, especially if cognitive decline has set in. For example, a concerned daughter in Scheibel and colleagues (2019, 6) explained in a letter to Social Services: 'It is a shame that it has come to this, but Mum has been in a very confused state which has become much worse recently.'

Unsurprisingly, then, the least involved were typically 'older old' adults (defined as 95+ years old by Scheibl et al. 2019) and those with dementia or other frailties (generally understood as higher propensity for cognitive, mental and physical impairments and difficulties recovering from them; Ko 2011). Lord and colleagues (2016) observed that older adults with dementia were given little choice about care transitions and it was upsetting to them not to be involved in the decision-making process about their own lives. Some expressed humiliation at being 'treated as incompetent' (Lord et al. 2016, 3); others complained about not being given any choices and having unrelated people making decisions for them (*e.g.* a care home manager). Taking over decision-making for older adults with dementia can happen despite the family and carers having the older adults' wishes in mind. Samsi and colleagues (2022) found that the possibility of a move to a care home was not discussed until the older adult's physical health and cognitive abilities had deteriorated to the point where the family no longer involved them in the conversations. In the case of 'older old' adults participating in Scheibl and colleagues' (2019) study, most were not sole decision-makers in the decision to transition to a care home. Other older adults were pressured into moving, had others' choices imposed on them despite voicing their preferences, or ended up being dependent on others to make a decision owing to being in a vulnerable situation. Similarly, Pocock and colleagues (2021) reported on a case of a frail older adult who had no choice in where he would live, as he was moved to a care home following a hospitalisation. The man explained that the decision came unanimously from his family members, while his voice was disregarded. He recalled the event with the words 'they beat me' (Pocock et al. 2021, 9), the phrase signifying the overruling of his wishes and his eventual resignation.

Even older adults with minimal care needs do not always have full autonomy to decide for themselves, despite having adequate abilities. Stevens and colleagues (2015) reported that while some older adults with minimal care needs chose to relocate based on their beliefs and needs, others had family members or doctors make decisions for them. In many cases, older adults doubted the decision was in their best interest but ultimately resigned themselves to others' choices. For instance, one woman stated that her niece was worrying about her, and she ended up being admitted to a care home, while in her opinion she 'could have carried on for a while' without relocating (2015, 97). Another woman talked about the influence of her doctor (likely on her family members): '[T]he doctor was there, and he nodded and said it is the best, and so they thought that if the doctor says that, it is not too bad' (2015, 99).

Generally, lack of involvement resulted in regret and upset. An older woman in Scheibl and colleagues' (2019) study was convinced to move to a home to be closer to family members but ended up regretting this decision because it resulted in losing friends from her previous care home while the family members visited infrequently. Lack of appropriate information-sharing could also lead to frustration and distress. An older man whose sheltered housing was flooded understood that he needed to relocate but was not informed that he would be moving to a care home rather than another sheltered house, leaving him feeling 'upset and misinformed' (Rhynas et al. 2018, 5). More broadly, when older adults were not given full information and others made decisions for them, the older adults felt left out and 'at the mercy of other people' (2018, 7).

Thus, regardless of the intentions of decision-makers, the exclusion often has negative consequences for older adults, diminishing their autonomy and wellbeing, whether they are fully capable or require some support.

1.2 Usefulness of involvement

Conversely, being actively involved in the decision-making can positively influence older adults' transition and post-transition settling period. All studies except for Kumpunen and colleagues (2019) reported a few cases of older adults who had some degree of choice in their relocation, often citing safety concerns or a desire not to be a burden. Although details about their lives in care homes were limited, their testimonies reflected greater acceptance and a more positive outlook: 'They ask you what you think of all the different ones … I just looked at two homes that was the choice. I think it's very good here' (O'Neill et al. 2020, 7). Even staying informed was seen as beneficial, as a resident who was moved owing to a care home closure believed keeping residents in the loop resulted in a smoother transition: 'I think we were well informed about what it was and I came here a couple of times to look around. I don't think it could have been done any better' (Leyland et al. 2016, 384). These examples suggest that being involved in the decision-making about their transitions to any extent can be beneficial to older adults.

2. The necessity of moving

The necessity of moving into care can arise gradually as older adults' health declines or suddenly owing to a life event (*e.g.* a fall or the passing of a spouse). In these situations, both the older adults and their families often felt that relocation to a care home was their only option, with many recounting a sense of being trapped by circumstances and forced to make difficult decisions during a crisis.

2.1 Triggers for moves

Situations where multiple factors led to the inevitable decision to move to a care home (described in all studies except for Kumpunen et al. 2019) were referred to as the 'tipping point' by Samsi and colleagues (2022). This could be triggered by a sudden event, such as hospitalisation owing to a new or worsening health condition, or by a gradual accumulation of long-term factors and a growing need for additional support. Sometimes this realisation came from older adults with dementia, stating that they started to feel the need for more help or that they did not want to burden their family members any longer: '[I]t does take a bit of the pressure off the main carer like [daughter] is to me' (2022, 1858). Many of the older adults seemed to understand that they had no other choice but to relocate. One relative stated, 'I think she realised that she couldn't really say no' (2022, 1858).

The older adults who recognised the necessity to relocate and made the choice themselves stated various reasons for doing so. From realising they 'needed a lot more looking after', through admitting to not being in a 'fit state mentally or physically', to explaining they 'don't like being alone' (Stevens et al. 2015, 98–99). A number of the older adults recalled the point at which they realised they could no longer stay at home (O'Neill et al. 2020). For example, an older woman explained, 'Well, I had a bad fall a few months ago and I wasn't really myself after that. I lost my confidence and of course they worried away about me and wanted to make sure nothing happened to me. You know you can't do this on your own. You have to have help. So that's where I am' (2020, 7). Another participant with a similar experience stated that he believed he had made the right decision to move. This sentiment contrasts with the feelings of those who reached the same point but had decisions made for them by others, highlighting the downsides of excluding older adults from the decision-making process.

Triggers therefore play a defining role in decision-making involvement, as they stem from transition-driving factors rather than the level of control each party has.

2.2 The role of family

Family members are often the ones to realise the need for a relocation. A daughter of a person with dementia recalled: 'My brother was taking her [home] and reali[s]ed there was just no way he could leave her at home, she was just in no state for that' (Lord et al. 2016, 5). Relatives often delayed care relocation decisions until (or even beyond) the situation became 'urgent' (Lord et al. 2016, 5), as they found the choice difficult. One relative explained, 'Emotionally I couldn't have done it earlier, because I love her at the end of the day. I did it when I could cope no more. When I couldn't give her the care she needed and keep her safe' (Samsi et al. 2022, 1858). This suggests that many families care about the older adults' wishes but sometimes cannot comply with them. For instance, Rhynas and colleagues (2018) reported a case of a son who did not want to admit his mother to a home despite her difficulties coping at home because she told him '[she] is terrified to go to a care home – he's trying hard to uphold her wishes, against the MDT [multidisciplinary team] advice' (2018, 7). However, waiting too long to plan for the possibility of relocation can be problematic, as it could be at a point when the older adults may lack the capacity to be fully involved, leaving others to make all decisions if little prior discussion was had about the issues (Lord et al. 2016). So while family can play a key role in recognising the need for relocation, their emotional struggles and the difficulty in making such decisions can cause delays, leaving little time for older adults to be sufficiently involved.

3. Timely planning

Timely planning involved older adults discussing and planning their potential relocation to a care facility while still being able to contribute to decision-making. Some families admitted to not having planned or doing so only in crises; others did not mention prior planning. Difficulties around planning were sometimes related to cognitive and emotional challenges associated with a dementia diagnosis, but those who planned ahead generally found it helpful.

3.1 Helpfulness of planning

Both older adults and relatives reported on by Samsi and colleagues (2022) found timely planning helpful both practically and emotionally. Emotionally, a person living with dementia explained that planning ahead for them was about slowly accepting their future or 'fac[ing] up to the fact' (2022, 1858). Practically, having researched homes and having their older relatives added to a waiting list to a preferred home was seen as useful for the future. Reaching a time of crisis without prior planning could leave older adults with no choice of homes as they are ushered into the first available room. An older man who had to move after hospitalisation recalled: '[T]he pressure was put on [my niece] to get me a home quickly so that is why I am here. All these places are all filled up you see' (O'Neill et al. 2020, 8). While the benefits of having plans in place were explicitly stated in only one study, the contrast with problems that arose where planning was absent also highlights its potential benefits.

3.2 Planning avoidance

The participants (family members of older adults with dementia) in Lord and colleagues' (2016) study admitted that they sometimes could not involve their relatives with dementia in decision-making due to the older adults' worsened state, often feeling overwhelmed by taking on that responsibility. At the same time, none had written records of the older adult's wishes from before their decline. The family members agreed that written documentation would have been useful, but all expressed hesitation about introducing it early, at the point of the diagnosis. However, this reduces the time available to have conversations about forward planning for care, as the course of the illness can be unpredictable. Scheibl and colleagues (2019) echoed the need for timely planning. In their study, older adults with mild to moderate disabilities were more likely to be involved in decision-making, while frail adults were often excluded or overruled, highlighting the need for early discussions and written documentation of wishes.

The reason for postponing certain discussions may be owing to perceived discomfort to the family members, the older adults or both. A wife of a person with dementia explained that she and her spouse were not yet able to talk about everything relating to possible future care: 'When I think about it I think there are areas that are still a bit taboo between us, maybe we're protecting each other' (Lord et al. 2016, 4). Others felt that discussing the potentially challenging future care decisions early on would add to the distress caused by the already upsetting diagnosis: 'I think that will worry people a lot … they will think the worst … let the patient get used to it a little bit, let it sink in a bit you know and see what progress' (Lord et al. 2016, 7).

Overall, this sub-theme highlights the contrast between the perceived usefulness of timely planning and the reluctance to plan in advance, along with some reasons for why this may be the case.

4. Factors for choosing a care home

This theme highlights the information older adults prioritise during care transition decisions. While location and finances were typically the first considerations, quality indicators like room features, staff support and social opportunities followed. Personal recommendations and visits often carried more weight than official reports. Familiarity with the care home and continuity in relationships and routines also played a key role in a smooth transition. Overall, personal factors (*e.g.* resident treatment) were valued more than practical ones (*e.g.* facility design), though both were considered.

4.1 Non-quality factors

Location and finances are likely among the first factors considered when choosing a care home. Kumpunen and colleagues (2019) explained that these non-quality factors are essential prerequisites that are addressed before participants can evaluate quality indicators, such as cleanliness of home or room sizes. These factors were further stressed by participants in Leyland and colleagues' (2016) and Lord and colleagues' (2016) interviews. Location was seen as desirable for varied reasons, such as being close to home, family or friends, but also to local amenities such as shops or public transport to retain independence. Closeness to friends may sometimes override closeness to family: 'The main reason for wanting to keep her [mother with dementia] up there [further away from the family] … to go to a nursing home … was because of her friends' (Lord et al. 2016, 4). Availability of space was another non-quality factor mentioned when deciding on care moves. An older adult who had to move to a care home after a fall at home recalled, 'When the bed becomes available well that's it, apparently you have to grab it' (O'Neill et al. 2020, 7). Non-quality factors thus typically served as prerequisites when considering a care transition.

4.2 Quality factors

Following the assessment of non-quality factors, quality factors, which directly influence the quality of care and the general experience of residents, may be considered (Kumpunen et al. 2019). Older adults considered factors including room size, view and location in the building, available facilities and personal-needs care when choosing a care home (Leyland et al 2016; Samsi et al. 2022). Older adults did not always put their health and care needs first, potentially seeing other quality factors as more important. A staff member in a care home was surprised to learn that an older woman with mobility issues was given a room upstairs but believed that 'it's the room she chose herself' (Leyland et al. 2016, 384).

Staff support for physical needs as well as to combat loneliness was also stated as an important factor by a person in a care home living with dementia: 'It's comforting that there are people here should you … feel you need somebody; that there's somebody here who can just steady your arm if you need, or a stick … and staff always listen to what you've got to tell' (Samsi et al. 2022, 1858). Participants in Kumpunen and colleagues' (2019) study similarly highlighted the importance of staff treatment, cleanliness, 'tastiness of meals' and social opportunities, with courtesy and respect during personal care and treatment of residents by staff listed at the top of quality indicators.

Quality indicators can typically be found online in inspection reports or directly on care homes' websites. However, Kumpunen and colleagues (2019) found that participants preferred information from personal or trusted sources over public materials, finding the advertised details like facilities and medical support less important and often unclear. Participants distrusted official information, relying more on personal experiences and family and residents' recommendations. While well-explained quality indicators helped identify homes to visit, the visit itself was crucial in making a final decision. One prospective resident suggested, 'Go back at different times and then, you know, eventually having looked at half a dozen you'll probably assess one that really suits you, you get the feel for it, it feels right for you' (Kumpunen et al. 2019, 92).

Overall, while quality factors play an important role in care transitions, decisions made by individuals or their loved ones were often based more on personal experiences and trusted word-of-mouth recommendations rather than formal rating systems.

4.3 Continuity of life

Finally, familiarity and the assurance of continuity in older adults' lives were important for many. Familiarity with the care home through its reputation or previous visits, along with knowing the staff and residents from prior visits or respite stays, was highlighted in many studies as an important factor in choosing a particular care home (Leyland et al. 2016; Lord et al. 2016; Samsi et al. 2022; Scheibl et al. 2019; Stevens et al. 2015). Being assured of continuity in their lives prior to relocation was important information to older adults. Leyland and colleagues (2016) reported continuity to be one of the factors being focused on to ensure a smooth transition between care homes for older adults. During the transition, staff in both the previous and the new care homes aimed to maintain consistency by ensuring that location and layout were as close to the original ones as possible, while also allowing older adults to bring some of their furniture and belongings. Other details were thought about as well, such as moving phone numbers, keeping newspaper deliveries, and the continuation of older adults' routines. Continuity of social relations such as friendships and staff was also important. One resident explained their feelings about the continuity of staff as pleasant and useful: 'Well you know them [staff from the old care home] a bit, and you can ask them things. Yes I think it is really, it's nice to know somebody isn't it' (Leyland et al. 2016, 387).

In another case, a care home manager explained how a resident moved to a potentially unsuitable care home because '[s]he wanted to move with [her friend] … Although whether she's rightly placed here or not remains to be see[n]. [She] would probably have benefitted from nursing care but obviously wanted the continuity of friendship' (Leyland et al. 2016, 383). However, Kumpunen and colleagues (2019) did not include continuity among key quality factors presented by care homes for decision-making, suggesting that this factor may not be explicitly presented by providers.

Continuity of life and familiarity appear to be important to older adults and their families when considering a move to a care home, but it is unclear how much focus providers place on these factors.

Discussion

This review explored the experiences of older adults within the context of SDM about transitioning to a care home in the UK. The systematic search yielded nine articles fitting the criteria. Although the aims of the studies varied (see Table 2), this review focused specifically on synthesising the older adults' experiences within the decision-making process. It provides a targeted snapshot of their perspectives among other decision-makers across different contexts. Four themes with nine sub-themes were identified through thematic narrative synthesis. These themes highlight the predominant lack of input from older adults in decision-making about their care transitions, even though involving them has been indicated as helpful for a successful transition. Despite the potential benefits of their inclusion, their voices are often sidelined during crises that demand swift action. Although involving older adults during a crisis may be challenging owing to the numerous risk factors their families and health-care providers must address, planning proactively for such situations could help ensure that their perspectives are included in these critical conversations. This was supported through narratives of those who did manage to plan. It was also found that older adults may prioritise information about personal rather than medical treatment within care homes over other quality factors, particularly when it is shared by trusted individuals or gathered during personal visits.

Relating to the theme of *Involvement in decision-making*, the exclusion of older adults from these decisions has been observed in other countries (*e.g.* USA, Canada, Hong Kong, Japan, Australia, Switzerland), often leading to challenging transitions, as it deprives them of autonomy over their own choices (Brownie et al. 2014; Heid et al. 2016; Sun et al. 2021). As the theme *Necessity of moving* indicates, a common factor leading others to take over decision-making is the presence of a crisis, such as sudden hospitalisation or family carer burnout, which necessitates placement in a care home (see also Dellasega and Mastrian 1995; Giosa et al. 2014; Magilvy and Congon 2000; Sussman and Dupuis 2012). While some may feel compelled to make these decisions for older adults to minimise physical risks (Fraher and Coffey 2011; Heid et al. 2016; Rhynas et al. 2018), there should also be a focus on the potential mental health risks that arise when older adults are excluded from decisions about their own care. Research has shown that unplanned, unexpected or forced transitions can make it challenging for older adults to settle into care homes successfully; such transitions can prolong the adjustment period, and are often accompanied by feelings of sadness, loss, suffering, loneliness, isolation, alienation, frustration, anger, anxiety and depressive symptoms (Bland 2005; Fraher and Coffey 2011; Keister 2006; Koppitz et al. 2017; Wilson 1997). Conversely, those involved in the process tend to experience better outcomes, including faster integration into care homes, a positive outlook on the transition, and feelings of comfort and safety in the homes (Chao et al. 2008; Gilbert et al. 2015; Johnson et al. 2010; Wilson 1997). The mental health risks should thus be considered alongside physical health risks, which often dominate the focus of other decision-makers.

Those involved in the transitions should also recognise the barriers that older adults may face when they attempt to involve them in decision-making. Some older adults may not realise they can act autonomously in these choices. For instance, many older adults tend to trust family members and medical professionals to make decisions on their behalf, assuming (often incorrectly; see Marks and Arkes 2008) that these individuals understand their values and wishes implicitly and would apply them within their professional or informed judgement (Bynum et al. 2014; Mignani et al. 2017; Wetzels et al. 2004). In such cases, others may assume that older adults prefer not to be involved. However, Basteians and colleagues (2007) found that older adults often seek a different kind of involvement; rather than direct decision-making, they value being included in discussions, receiving clear information and experiencing a compassionate, person-centred approach from professionals. The synthesis in this review also confirms that being included and informed is, in itself, important to older adults. This is an important finding which can partially substitute older adults' full control over the decision-making process in those situations when others must prioritise the risk to their lives.

The way individuals consider information will also vary depending on the situation they are in. This review's synthesis suggests that non-quality factors, such as location, costs and bed availability, serve as prerequisites to considering quality factors (*Factors for choosing a care home*). Costs are especially important in countries where a significant portion of care is self-funded (*e.g.* Hibbard and Peters 2003; Nguyen and Häkkinen 2006; Victoor et al. 2012), as well as in systems under pressure to prioritise those with the greatest need – especially amid increasing demand for care transitions, as currently observed in the UK (Tanner et al. 2024). Beyond this, quality factors can be challenging to understand and integrate into decision-making, regardless of age (Castle 2003; Fasolo et al. 2010; Trigg et al. 2018). Some of the reasons for this were the sheer volume of information that needs to be processed and the use of non-standardised terms and indicators for evaluation (*e.g.* percentages, star ratings). Using more salient presentation strategies such as narratives, visual cues and framing information in terms of potential losses rather than gains could help people easily cognitively process and understand the information (Hibbard and Peters 2003).

Taken together, the above highlight the importance of SDM throughout the process. The lack of communication between older adults and other decision-makers hinders SDM, in which each actor has a distinct function and responsibility (Elwyn et al. 2012). Without effective information-sharing, family members and professionals may unintentionally prioritise their own wishes or apply their own perceptions of risk, which can differ significantly from those of the older adult (Clarke 2000; Clarke et al. 2010; Marks and Arkes 2008). While exchanging this information verbally can be helpful to improve the agreement on care decisions among older adults and other decision-makers (Roberto 1999), conversations alone may not improve the family's understanding of the older adult's wishes (Hines et al. 2001). This discrepancy might stem from decision-makers projecting their own wishes onto those of their older relatives (Marks and Arkes 2008; Roberto 1999). Written advance care planning and directives are generally beneficial for both older adults and decision-makers, but their acceptance has been mixed, with family members and other decision-makers often more willing to use these tools than older adults themselves (Hines et al. 2001; Mignani et al. 2017).

To encourage the use of advance care planning, it may be necessary to redefine what planning represents for individuals. Sudore and Fried (2010) argue that advance care planning should focus on preparing individuals to make the best possible decisions when the need arises, rather than committing to decisions during the planning phase, which is often constrained by incomplete and inflexible information. Such reframing could encourage individuals to reconsider its value. Additionally, timing of planning is also critical. Mignani and colleagues (2017) recommend a gradual, sensitive introduction to advance care planning with professional guidance. Early planning soon after a diagnosis of dementia, although distressing (Lord et al. 2016), could help avoid delays that can make decisions more difficult later. The goal is to engage in conversation with older adults as early as possible following a dementia diagnosis, while taking care to minimise distress.

Future research

This review highlights two key areas for future research. First, there is a need to improve the involvement of older adults in decisions about their care arrangements to prevent the negative consequences of their exclusion (as identified in this article). Second, given the significant role that family carers play, it is crucial to provide them with the necessary support and readiness for SDM with older adults and other stakeholders.

While this review identified several areas explored in recent research (*e.g.* reasons for care transitions, decision-makers involved and prioritised information), future research should also explore the challenges faced by older adults, the factors that support their decision-making, potential sources of assistance, and barriers to effective planning. To prioritise the perspectives of older adults, future research should recruit individuals who are contemplating or actively planning a move to a care facility, as well as those who have already transitioned. While studying those who have already moved provides valuable information on their experiences and the consequences of their decisions, following individuals in real time as they consider or plan their move offers a unique opportunity to observe decision-making as it unfolds. This approach may also help capture a more diverse demographic, since care home residents in the UK are currently predominantly white (97.5 per cent; Office for National Statistics 2023).

Families and friends, who play a key role in decision-making and often experience emotional strain as a result, should also be considered. Their experiences with care transitions should be explored to ensure that they receive adequate support, both informally and legally. Notably, none of the studies in this review explicitly addressed lasting power of attorney (LPA), a legal appointment which takes effect only once the appointer is deemed to lack capacity. While many of the points raised in this review – such as the need for conversations and written directives – remain relevant within the topic, future research should also examine to what extent legal appointments influence the decision-making process. This is particularly relevant with the recent increase of LPA registrations in the UK (Office of the Public Guardian 2024).

The findings from older adults and other decision-makers could inform a document, such as a decision aid, which would help older adults and their relatives prepare for and guide them through the process. Unlike the decision aids available now, a new aid should be more user-friendly, non-legally binding and flexible, highlighting their ability to change their wishes over the following years, along with the changes in their health, preferences and availability of care. Unlike aids considered by participants in the synthesised studies (*e.g.* Lord et al. 2016), information about care options other than care homes should also be made available.

To ensure a comprehensive understanding of the SDM process, involving various stakeholders is vital. Conducting focus groups can facilitate mutual awareness among different groups. Educating each group about older adults' preferred involvement might ease reported stresses among family carers. While family members often desire involvement from older relatives, they may assume full responsibility owing to perceived information or cognitive advantages, an aspect warranting further investigation. Moreover, exploring the most effective engagement of health-care professionals, given their significant role in care decisions, is crucial.

Strengths and limitations

The use of four databases, guided by an information specialist, was appropriate for the scale of this study; however, this approach represents a limitation, as relevant articles may have been missed. To mitigate this, a thorough backward and forward citation search of key articles was conducted to capture a broader range of literature. A limitation of the synthesis itself was the reliance on both direct quotes from participants and the interpretations provided by original authors, which may have introduced some bias. To address this limitation, participants' direct quotes were prioritised in the synthesis to ensure a closer reflection of their perspectives. Finally, a limitation of the findings and implications of this review is that the synthesised studies did not fully capture the perspectives of the target population, namely, older adults. More than half of the studies relied more on other stakeholders' accounts than on input directly from older adults, with limited explanation of how this was addressed in their analysis. Additionally, most studies lacked socio-demographic diversity and few reported efforts to recruit more diverse participants. This means that any implications from this review should be interpreted with caution, as they may not fully represent the experiences of older adults from diverse backgrounds or their role as central decision-makers.

A strength of this review is the incorporation of reflexivity into this manuscript, which distinguishes it from the majority of the synthesised articles. By addressing potential author biases, readers are provided with greater transparency, a critical element in qualitative research. Additionally, this review keeps older adults central during transitional periods, embedding their experiences within broader narratives of other decision-makers, while taking great care to maintain the prominence of their perspective.

Conclusion

This work has reviewed nine UK-based studies with a focus on exploring older adults' experiences with being involved in decision-making about their future care arrangements, specifically with the transition to care homes.

Through a narrative synthesis, four themes were identified which shed light on the paucity of older adults' involvement in the whole process, the various reasons for this, the barriers they face, the situations which necessitate the relocations, as well as the kinds of information that seem to be important to older adults in the process.

This review makes a novel contribution by uniquely centring on older adults' experiences in decision-making about care transitions, rather than focusing primarily on other decision-makers or on decision-making about health care, as previous reviews have done. It highlights the need for greater involvement of older adults, early planning and the role of personal experiences and preferences in the relocation process. The findings emphasise the importance of respecting older adults' autonomy, preferences and emotional wellbeing throughout this transition. While the articles analysed in this review are based in the UK, the results broadly align with findings from other countries, despite differences in health care and social systems. By addressing these themes, professionals and family members can work together to enhance the relocation experience for older adults moving into care homes.

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