

RESEARCH ARTICLE

Professionals' views on the “optimal time” for people living with dementia to move to a care home

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Objective: The decision about the best time for a person living with dementia to move to a care home involves the individual and others, particularly family. However, little is known about care professionals' views on the best time to move, particularly those with decision-making authority. This study investigated social workers' and care home managers' views on whether there is an “optimal time” for a move.

Methods: A qualitative, phenomenological approach was employed, using semi-structured interviews with 20 social workers and 20 care home managers in England; all with experience of advising people living with dementia about a care home move and making decisions about funding or acceptance. Interviews were audio-recorded, transcribed, and analyzed thematically.

Results: Four overarching themes emerged from the data: (1) staying at home for as long as possible but avoiding crisis, (2) balancing risks proactively and anticipating triggers, (3) desires for the person living with dementia to be involved in the decision, and (4) the significance of funding in enabling choices about a care home move.

Conclusions: Deciding on the timing of a care home move is context and person specific. Two professional groups with substantial experience of this among their client group both recommended proactive deliberation but funding was overall the deciding factor in the extent to which they considered choice was possible. Future research should avoid seeing all care home moves as negative and explore how practitioners can best encourage discussions prior to crisis point about care home options.

KEYWORDS

care home, decision, dementia, qualitative research, social work

1 | INTRODUCTION

Deciding whether or when to move to a care home can be difficult for people living with dementia and family members.^{1,2} The optimal time of such moves has not been adequately addressed,³ but was identified as important to family carers and professionals by the English James

Lind Alliance and Alzheimer's Society research priorities setting exercise.⁴

In England, the term “care home” refers to “a place where personal care and accommodation are provided together”^{5(p26)}; this can be with or without nursing care. Internationally, care homes are known by different terms (eg, long-term care facility or nursing homes).⁶

Rather than shared decision making, there is some evidence that relatives decide if, and when, a move to a care home is to be made.^{7,8} However, professionals may be substitute decision makers or may influence

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such decisions. Under the Care Act 2014 in England, social workers must promote the wellbeing of people in need of care and support. Here, a social worker “personates” the local government authority in making decisions about entitlement for funding to pay care home fees, and may help secure a care home place, or provide information. For those paying their own care home fees, care home managers are often the first contact for the family, and generally, it is they who decide whether their care home will be able to meet the needs of potential residents.

There has long been debated in the UK about the need to take a balanced view of moving to a care home, portraying it as potentially a “positive choice” for some people rather than inevitably negative.⁹ A recent literature review investigating if there was an “optimal time” for people living with dementia to move to a care home, found some evidence from carers’ perspectives but little from the perspectives of people living with dementia, or of professionals.³ This present study therefore aimed to explore social workers’ and care home managers’ views on the “best” or “optimal” time for a person living with dementia to move to a care home in the English legal, policy, and funding context.

2 | METHODS

2.1 | Approach

The study took a qualitative, phenomenological approach, using semi-structured interviews with 20 social workers and 20 care home managers with experiences of supporting people living with dementia to move to a care home (with or without nursing). These two professional groups were the focus of this study due to the centrality of their involvement in the decision-making process about a care home move, namely funding, information, and acceptance.

2.2 | Participants and recruitment

Directors of three English local authorities in south-east England were approached and agreed to take part in the study. The local authorities were chosen to represent diverse socio-demographics and geographical areas in urban and semi-urban communities. The researchers provided an overview of the study and a participant information sheet for managers to disseminate to staff asking interested social workers to either contact the researcher direct or tell their line-manager, who would then inform the researcher via email. The researcher also attended management meetings to explain the research and met with groups of social workers. “Social worker” participants were eligible for the study if they worked in social work-related roles, either as registered social workers or in supportive roles (ie, care manager working under the supervision of a social worker) and had experience of advising people living with dementia and their carers about moving to a care home. Twenty social workers (seven senior social workers, ten social workers, and three care managers) agreed to participate. Most of their clients lived at home, but five social workers were based in hospitals and one worked across both settings.

Key points

- Both social workers and care home managers believe that most, but not all, people living with dementia want to stay at home for as long as possible.
- Both social workers and care home managers recommend that whether and when to move to a care home should be discussed with people living with dementia early in their condition.
- Professionals often recommended the use of residential respite or joining a waiting list at a preferred care home as a potential “stepping stone” toward a permanent move.
- Both professional groups acknowledged that individuals who fund their own care have more options about the timing of their move than those state funded and both groups provided advice on funding implications.

Care home managers were recruited from across the south of England to cover a broader area. Chief executives and managers were approached by the researchers (JM/LC) and informed about the study by e-mail and telephone. Four non-profit care home providers agreed to take part, and head-office directors either sent an e-mail to care home managers informing them of the study or gave permission for the researcher to approach their care home managers direct. Two small privately owned care homes also participated. In total, 28 care homes were approached directly by the researcher and 18 care homes took part. Most care homes were not-for-profit/charity run organizations, varied in size (18-82 occupancy), and offered a range of services (residential, nursing, specialist dementia care) and funding options (self, local authority, continuing healthcare (from NHS)). Potential participants were provided with an overview of the study and a participant information sheet and asked if they would like to be interviewed. “Care home manager” participants were eligible if they assessed potential new residents and made decisions about offering them a place. Of the 20 participants who agreed to take part in the research, 17 were registered care home managers, two were dementia specialists overseeing the care of residents living with dementia, and the third was a deputy manager. Nineteen interviews were conducted across the 18 care homes: one was a joint interview with a manager and her deputy, and two other participants worked within the same home. Table 1 summarizes participant characteristics.

2.3 | Data collection

Face-to-face interviews were conducted in a quiet area at the participants’ workplace, with minimal distractions and where confidentiality could be maintained. Participants were asked to complete a short

TABLE 1 Participant characteristics (n = 40)

Characteristics	Social workers (n = 20)	Care home managers (N = 20)	Total (N = 40)
Gender			
Female	18	16	34
Male	2	4	6
Age (years)			
20-29	3	0	3
30-39	6	5	11
40-49	8	5	13
50-59	1	5	5
60-69	1	2	3
70-79	0	1	1
NK	1	2	2
Ethnicity^a			
White	9	15	24
Mixed	2	0	2
Asian	4	3	7
Black	5	1	6
Experience (years)^b			
0-4	5	8	13
5-9	10	4	14
10-14	4	3	7
15-19	0	2	2
20-24	1	3	4
Qualification (Highest)			
NVQ Level 3	3	1	4
NVQ Level 4/HE Cert.	0	3	3
NVQ Level 5/HE Dipl.	0	4	4
NVQ Level 6/Bachelor's degree	13	9	22
NVQ level 7/Master's degree	4	0	4
NK	0	2	2

^aAbbreviations: HE Cert., Higher Education Certificate; HE Dipl., Higher Education Diploma; NK, not known: participant chose not to provide this information; NVQ, National Vocational Qualification.

^aUK Census ethnic group categories (White; Mixed/multiple ethnic groups; Asian/Asian British; Black/African/Caribbean/Black British; Other ethnic group).

^bYears worked as a social worker or care home manager.

demographic form before interviews commenced. The researcher (LC) used a topic guide as a prompt to ensure all topic areas were covered. This guide contained questions about (1) participants'

experience of the processes for a person living with dementia to move to the home, (2) their views on an "optimal time" (if any) to move; (3) their experiences of discussing the cost and responsibility for paying the care home fees with people living with dementia and their families; and (4) the typical responses of people living with dementia following a move. The findings reported in this paper concentrate on professionals' views on the timing of a move to a care home; specifically:

- Is there an "optimal" time for a person living with dementia to move to a care home?
- Is it best to move to a care home in the later or earlier stages of dementia?

Participants were encouraged to speak as freely as possible about their views and experiences. All interviews were digitally audio-recorded, and transcribed. Interviews lasted between 25 and 90 minutes. Field notes were made following the interview.

2.4 | Ethical requirements

Written consent was obtained from all participants, who were assured that participation was voluntary, they could withdraw from the study at any time, and their contribution would be anonymous and confidential. However, participants were told that confidentiality might be broken in the event of disclosing risk of harm to themselves or another person. Full ethical approval was gained from the Health Research Authority Social Care Research Ethics Committee: 16/IEC08/0035.

2.5 | Data analysis

Transcriptions were analyzed using the principles of thematic analysis.¹⁰ Transcripts were read repeatedly to gain familiarity and generate initial codes. Codes were then searched throughout the data and a table of themes produced. Further iterations of the interpretations were conducted until no new themes could be identified, and theoretical saturation had been reached. The initial coding and collation of a table of themes were conducted by LC. Emerging themes were agreed and finalized by all authors, resolving any disagreement through discussion.

3 | RESULTS

Four overarching themes were found from the data: (1) staying at home for as long as possible but avoiding crisis, (2) balancing risks proactively and anticipating triggers, (3) desires for the person living with dementia to be involved in the decision to move, and (4) the significance of funding in enabling choices about a care home move.

3.1 | Staying at home for as long as possible but avoiding crisis

When asked about the timing of a care home move, both social workers and care home managers concurred that most people living with dementia wanted to live at home for as long as possible, and therefore this choice should be supported:

I think it depends on the person. I mean, obviously people want to remain in their own homes for as long as possible. Especially if they are with family or a partner and they are still living at home. They obviously want to remain there as long as they can. Sometimes it's good to keep going for as long as [possible] (care home manager, 06)

This was particularly important in terms of retaining personal control, independence, and autonomy. Some participants were concerned that an individual would lose these if they moved to a care home. However, both groups of professionals acknowledged that staying at home for “as long as possible” usually risked the person living with dementia and their carer (in the circumstances where there was a willing family member) exhausting all care options and this increased the chances of a move occurring at a crisis point. Most argued that a crisis, which for both groups related to a breakdown in care or unmet needs, was not an ideal time to move to a care home but reported that this often happened:

It's hard to say what is that [optimal time for a move]? It's definitely not when they come into hospital and reach crisis point [slight laugh] that's not the optimal time. That is often what we see (social worker, 08).

Finding the right time between staying at home for as long as possible but avoiding crisis seemed their aim in discussions with people living with dementia and families.

3.2 | Balancing risks proactively and anticipating triggers

Determining when the move to a care home should occur was recognized as difficult for all involved and most thought that there was no prescribed list of circumstances, situations, or events that dictated this. Both professional groups viewed the timing of the move to be person—but also context—dependent:

So, for me, it's really, really, really, um, individual. Um and it depends on so many other factors like family, friends, what support [they are receiving], their level of dementia, and most importantly what they want (social worker, 07).

However, all participants acknowledged that risks and safety of the person living with dementia (and sometimes carers) while at home prompted considerations of change. Social workers referred to “triggers” or “tipping-points,” a moment or a situation that initiated the decision-making process for the person living with dementia to move to a care home. This was usually when risks to their well-being were becoming dangerously high and frequent, the carer was no longer able to offer substantial support, there had been an injurious fall with hospitalization, and, in summary, the person living with dementia was now considered to need 24-hour support, supervision and care, and arrangements for thinking about a move could start:

Their [person living with dementia's] risks are 'bubbling'. [...] If they are starting to 'bubble' and family are anxious, it needs to kind of tip before, it then becomes a high risk to then say “okay, being at home is no longer [an option]” (social worker, 03).

3.3 | Desires for the person living with dementia to be involved in the decision to move

There was a consensus among both groups that the person living with dementia should be involved in the decision-making process, but this usually was far harder in the later stages of dementia or in a crisis, because the person no longer had mental capacity to make decisions, was physically unwell, or too distressed. In this respect, it was better if decisions around a move to a care home had been raised or planned in advance. While professionals understood that discussions about future care wishes were daunting to some families, they considered that they should be attempted:

And we need to be brave enough to say to people, “look you know you could drop dead with a heart attack tomorrow, but if your dementia progresses you'll live long enough and it has an impact on your life, what would you like [to happen]?” (care home manager, 18).

Despite most participants holding the belief that people living with dementia should remain at home for as long as possible (see above), many suggested an early move to a care home might be beneficial for some people, as the person might settle more easily and be able to make their preferences and themselves known. Care home managers reported that this helped care staff get to know the person before the symptoms of dementia became severe and staff could therefore offer more individualized or person-centered care.

When people living with dementia had not been able to plan for future care (such as appointing a proxy to make decisions about their welfare) or move to a care home early, it was the social workers who often had to make “best interest” decisions on their behalf (under the Mental Capacity Act 2005) if no one else was authorized to do so; in

doing so they tried to adhere to the previously expressed wishes of the person living with dementia as best they could:

She [person living with dementia] was so vehement about wanting to stay at home that we had to do all in our power to keep her at home, even if it meant things like ... she did fall down the stairs, because she refused to put her proper slippers on. We knew that was a risk. But we knew that she actually wanted to stay at home, right the way through. And so, I was very reluctant to [move her] (social worker, 06).

When faced with reluctance to move, both groups of professionals thought trying periods of residential respite helped people living with dementia to experience what a long-term move might be like. Joining a care home waiting list was also viewed a helpful stepping-stone towards a move:

At least start the ball rolling and build up a relationship with the [care] home that you would really want to move in. I absolutely welcome people if they wanted to come and put their names down on the waiting list... If they just want to come and have lunch once a week or something and just sort of take part in a little bit of the [care] home, I wouldn't have an issue with that... I think that would be a really nice way of sort of introducing them to the home and how the home works. And then, you know, they can just sort of gradually come maybe twice or three times a week, four times a week until they are ready to come in full time, in an ideal world (care home manager, 11).

3.4 | The significance of funding in enabling choices about a care home move

While both groups of professionals believed that people living with dementia should be able to make the decision if or when to move to a care home themselves, they acknowledged that the option to move early was only available to those who were self-funding their care. Those reliant on state (local authority social services) funding would not be eligible until their need for support increased to a level that met the local authority threshold:

And the other thing to consider is like, if you're self-funding a placement, that's fine, you can make the decision when you do. But actually, social services won't consider putting someone in a placement unless they actually need it. So um, it's a bit difficult really (social worker, 17).

One care home manager recounted how two people in the early stages of dementia had recently sold their properties, moved in, and

settled well in the care home. These early moves had reportedly been undertaken so that they might not experience the distress that they envisaged any move might give rise to in the later stages of their dementia, and to maximize their feelings of control over their current and future care.

Both social workers and care home managers provided information and advice about England's system of means testing in social care to families. For a small group of care home residents, and reflective of the long-standing debate in England about care funding,¹¹ social workers advised about the risk of private funds running out and the potential consequences, which might include a move to a cheaper care home willing to accept local authority funding. Their role and that of the care home managers taking private payers was to prompt consideration of financial matters in the longer-term as well as present time, and many suggested that these matters had not been addressed previously:

The families want to provide the best they can for their mum or dad and don't necessarily think about what might happen when they run out of money. I think, I always say to people, you know, you have to have that frank conversation with the [care home] management and ask them if they would keep your mum or dad on social care funding should that happen.... (social worker, 09).

4 | DISCUSSION

Care home managers and social workers maintained that people living with dementia should be supported to live at home for as long as possible, and for as long as they wished.

They reflected national policy in England and elsewhere¹²; however, their views were more nuanced and reflected their experiences that for some people an early planned move might be their choice.

Escalating risks and concerns about safety for people living with dementia in their own homes are well documented.¹³⁻¹⁵ This study additionally highlights the importance of contextual issues that affect the timing of the move, such as level of social support, and needing 24-hour care and supervision. Lack of social support could lead to a crisis where a move to a care home might seem the only option.

A pervasive theme throughout this present study was professionals' belief that more could be done to involve the person living with dementia in deciding if and when to move to a care home, and that early conversations about future care needs with the person when they are able to do so may help prevent crises developing. Other studies have also found that the "voice" of older people with and without dementia or cognitive impairment is "lost" from this important discussion but others' views, such as family carers and professionals, take precedence.^{7,16} While the need to include people living with dementia in any decision is not a new suggestion,⁸ the timing may need to be considered post-diagnostically such as when discussing options to appoint proxy decision makers.

Involving and consulting people living with dementia is not just an ethical or human-rights principle; findings from a systematic literature

review suggest that a successful transition to a care home maybe fostered by input from people living with dementia in the decision-making process.¹⁷

The findings on the timing of moving to a care home in this present study highlight how choices about such a move most often affect those who have the financial resources to pay for their own care. For those needing public funding their choice of time to move is affected by the resources available to local authorities (with some small exceptions for NHS funded individuals). However, even when a person has the funds to meet care home fees, local care home markets and supply are of influence, affecting whether there are places available.¹⁸ There are also consumer-behavior differences between those who have made preparation by way of trying out a care home by visiting or staying temporarily¹⁹ and those who have not. Some of these variations were reflected in the findings of this present study.

Our study showed little differences between the two professional groups except care home managers were more likely to suggest the advantages of an early move for both the person living with dementia and care home staff. For social workers the possibility of an early move was less frequently recommended since most of their clients were not in a financial position to consider making a move without being in severe need or at crisis point.

4.1 | Strengths and limitations

This study is the first to explore professionals' experiences and views on the optimal time for a person living with dementia to move to a care home. Previous research in this area has only documented a case study exploring a social worker's experience supporting a person with dementia to move to a care home.²⁰ Our study interviewed 40 professionals from across England and gained a broad variation of experiences across care settings and areas. However, there were limitations to the study as it was a small convenience sample; different patterns of decision-making might appear with a wider sample. Case notes were not scrutinized and those interviewed may have been keen to present positive views of practice. In addition, there may be other professionals involved in the decision to move to a care home such as community mental health nurses, occupational therapists, general practitioners and managers of other services (eg, day centres, domiciliary care), whose views have not been represented in this study. However, the two professional groups in this study were chosen due to the principal role they play in terms of providing information and accepting a resident or agreeing public funding during the decision-making process.

4.2 | Practice and policy implications

Ambitions to create a dementia pathway following diagnosis may fall short if wider dementia contexts are not addressed such as the

availability of care home places, variations in preferences, and the decision-making role played by care home managers and by social workers. Our study suggests the importance of discussions about living arrangements early on, post-diagnosis, such as when information is given about proxy decision-making or advance care planning, and of recording preferences that can be shared with local authorities or other advisors. The avoidance of crisis may not always be possible but some contingency planning might be of assistance to minimize sudden or irrevocable moves triggered as a crisis response.

5 | CONCLUSION

The implications of this study's findings highlight the need to discuss anticipatory care arrangements with all stakeholders, including the person living with dementia. Future research focusing on the intentions of care pathway mechanisms to support post-diagnostic support of people living with dementia might be usefully developed to include key professional decision makers such as care home managers and social workers. In addition, studies focusing on the views and experiences of people living with dementia who have or are about to make a move to a care home are needed.

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CONFLICT OF INTEREST

JM is a Trustee of the Orders of St John Care Trust.

AUTHOR CONTRIBUTIONS

The research question was initiated by KS and JM. All authors designed the study and LC undertook data collection and drafted the paper. Thematic analysis was initiated by LC and verified by KS; with discrepancies verified by JM. All authors contributed to the drafting of the paper and agreed on the final paper for publication.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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