

Investigating 'optimal time': Perspectives on the timing of people living with dementia moving into care homes

RESEARCH FINDINGS

Best or 'optimal time' (if any) for a person living with dementia to move to a care home is individual, not necessarily related to symptom severity

People purchasing their own care have some scope for choosing timing of a move, but many decisions occur at times of crisis or distress

Care home place availability influences decision-making; linked to the home's proximity and perceptions of quality

Many relatives feel they shoulder the burden about deciding on a move and its timing – and receive little information or advice to help them

Some people living with dementia have made their views known about moving to a care home and this helps relatives with decision-making

Care home managers report often counselling relatives about the processes of a care home move



BACKGROUND

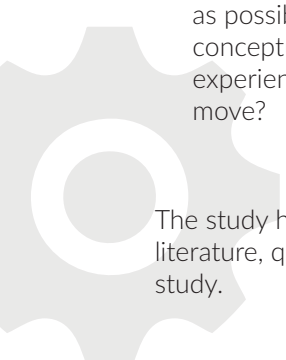
Moving to a care home is sometimes perceived as a last resort for someone living with dementia, with limited options and low expectations of care. A move is cloaked in negative terminology in the media, and practice and research literature; and the person living with dementia is often seen as passive, with words used such as “placed” and “abandoned”. Many older people, people living with dementia and the general public fear moving to a care home.

With increasing numbers of older people living with dementia and predictions that there will be declining numbers of family carers, deciding when the right time is (if any) to move to a care home is an important question.

The study

A three-year study was conducted addressing the following questions:

1. What factors in the decision-making process led to a person living with dementia moving to a care home?
 - a. Is it condition-specific (severity of dementia, number of years since diagnosis, other health needs requiring nursing care)?
 - b. Is it contextual (level of carer stress, absence of a carer, increasing costs of providing care at home, knowledge of a ‘very good’ care home)?
2. What is the role of the person living with dementia in the decision; role of family or carers? What is the role of care home managers?
3. “Optimal time”: What do professionals advise carers and people living with dementia about the best or optimal time (if any) to move to a care home (‘early’ to ease ‘settling in’ or as late as possible)? Do people living with dementia conceptualise an ‘optimal’ time? What are their experiences and beliefs around timing of this move?



The study had three parts: a systematic review of literature, qualitative interviews and a factorial study.



FINDINGS

■ SYSTEMATIC REVIEW OF LITERATURE

A thorough search in six English language electronic databases was conducted to identify gaps in understanding (Cole et al, 2018). Papers were screened against established inclusion criteria and rated for quality.

Sixteen relevant papers, and seven overall themes were identified through thematic analysis and data extraction: (1) what happened before the move, (2) planning 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.

‘Timing’ of the move was largely absent, and the decision-making process appeared ongoing. The feelings of carers and people living with dementia strongly influenced the decision, and whether both felt ‘ready’ for the move. Negative societal perceptions of care homes also appeared to affect timing, with emphasis on it being a “last resort” after exhausting other home care and social support options.

The findings were used to inform the development of interview topic guides for qualitative interviews.

■ QUALITATIVE INTERVIEWS

Following ethical approval, 21 family carers, 5 residents living with dementia (who had recently moved to a care home), 20 social workers working with people living with dementia, and 20 care home managers were interviewed.

They were asked about circumstances around moving to a care home, decision-making processes; what went well, what they might do differently; what advice they would give a friend living with dementia considering moving to a care home. All were asked to focus on ‘timing’ and whether, in their opinion, this could have been done differently.

Social workers

- Managing the risks and safety of the person living with dementia plus the family carer’s ability to continue with level of care at home were paramount in their efforts to promote the person’s well-being, and generally determined the timing of the decision to move.
- Many held strong beliefs that people living with dementia should continue to live at home for as long as possible.
- The wishes of the person living with dementia were highly influential in their decision-making, but a ‘best interests’ decision may be needed.

FINDINGS

- Social workers acknowledged that many people living with dementia and carers knew very little about adult social care funding systems especially what they would be required to pay and for how long.
- Many suggested carers and people living with dementia try respite or short-break care to experience the reality of care home life and possibly prepare for a long-term move.

“So it's kind of constantly looking at the risk, I think and weighing up. Is that a risk that we would be willing to take? Is there something we can do to kind of prevent that risk to get them back home [from hospital]? But if we have kind of ruled out everything, then we will suggest that maybe a [move to a care home] would be the better option”. (Social Worker 08)

Care home managers

- Most felt that determining “optimal time” for a move to a care home was individual, contextual and not dependent on the ‘stage’ of dementia.
- An early move to a care home had the benefit of care staff being able to get to know the person living with dementia before symptoms’ severity increased, thereby helping person-centred care. However, they were also aware that this needed to be balanced against most older people’s wish to stay in their own homes for as long as possible.
- An early move also means that the resident living with dementia might be more likely to be involved in the decision. Many managers thought that it would be helpful for people living with dementia to make future care decisions when they are still able.

- Many discussed how residents benefitted from the social interactions and activities in the care home, which they often lacked when living at home, and this could confirm to relatives that the right decision had been made.
- The managers said that joining a waiting list was a way of preparing for a long-term care home move. They also observed that respite and/or frequent short visits (e.g. for a coffee morning or a meal) before they moved benefit the person living with dementia since the surroundings, staff and residents become familiar.

“We write to people every three or four months and say “are you still interested and do you still want to be on the waiting list?” A lot of people say “we are managing all right at the moment, but we want to stay on the list”. But they don't actually say [that] they are making their own decision about [whether it is] the right time, really”. (Care Home Manager 05)

Family carers

- Decisions to move a relative to a care home were often highly emotional, with experiences of frustration, grief, guilt and sorrow. Many keenly felt the responsibility of making the decision on their relative’s behalf and tended to ruminate on whether they had done the right thing long after the move.
- Many described constantly weighing up the risks and benefits of their relative affected with dementia living at home before the eventual move.

- Some people had been on care home waiting lists when a place became available; carers weighed this up with their ability to cope at that point.
- Respite or a short stay in a care home had been accessed by some prior to a permanent move.
- Carers and people living with dementia valued the “feel” of a care home, caring staff, convenience for visiting (for example, proximity to the family) when making a decision to take up a vacancy.
- Many family carers complained about the lack of support from the local authority’s adult services, especially if self-funding. They felt deeply frustrated with not knowing where to turn to for specific advice, especially regarding care home payments and entitlements (of which they had limited knowledge or understanding, even when given general information), not knowing how long savings would last and what would happen if they ran out. Many relied on family networks for support, but this sometimes threw up conflicting opinions about what was the ‘right time’.

“She was not ready [in 2013] to come into a home. She used to still go out to the shop and get her paper and do all that. Okay, used to leave her credit card all over the place! [laughs] But I think it was the right time for her to go into a home [in 2017]. I think, I suppose we could have done it a few months earlier, perhaps. I think it was alright. That was why it was November and we thought shall we wait until the New Year. No we won't. We have got to move her” (Relative 01)

FINDINGS



- (1) ability of a family carer to continue caring;
- (2) amount of support received from care staff;
- (3) risks and safety when living at home;
- (4) wishes of the person living with dementia.

These were incorporated into a 'skeleton' short case story about a fictitious person living with dementia, Jane, who lives at home with her husband. 54 possible stories were constructed, and a survey in which each variation contained seven randomised case stories asking: "would you suggest that Jane move to a care home or continue living at home?"

A total of 100 surveys (the target number) were completed by dementia practitioners in the position of making such a recommendation (e.g. social workers, dementia advisors, general practitioners, nurses, care staff, and so on) in England. Of these, 78% were female; 54% were aged 50 years and over; 81% were White British; 21% were nurses while 18% were social workers.

Regression analyses were conducted, and findings indicated that strongest associations (in descending order) were:

- (1) the preference of person living with dementia was prioritised foremost, followed by decreasing ability of carer to support;
- (2) increasing levels of risk; and
- (3) increasing levels of home care provision.

This suggests that practitioners seek to maximise the amount of home care support they can obtain for a person living with dementia wishing to stay at home before they recommend a move to a care home.

"It's up to you to find a care home and... this is new to me... brand spanking new. We haven't got a clue. So we go to the experts and say, "tell us what to do and tell us who to go to and who is going to be good and who is not and I will pay" and they still say, "No. You've got to sort it out yourself"" (Relative 12)

Residents living with dementia

- People living with dementia expressed strong feelings about the move; with some stating there had not been any other options for care and support at the time of moving to a care home. There was general awareness that they had needed "back up".
- A range of involvement in the decision was recalled; from it being made for them to being more actively involved.
- There were strong indications that involving the person living with dementia in the decision had benefits in helping them adapt to

living in the care home; however the sample for this study was very small.

Resident: Well, I just accepted it because I could see that we needed some help, we needed some family near us. I wasn't happy to leave there, because I was so happy there [mmm]. And it has been quite difficult, but I've made myself do it.

Interviewer: Yeah, yeah. And what kind of help did you feel you needed?

Resident: Well, back up. It wasn't physical help and it wasn't help to do with the housework or anything like that [mmm], but we felt that we needed somebody near us to back us up over things. (Resident 02)

■ FACTORIAL SURVEY

Findings were collated and distilled from all participant interviews into four overarching themes:

CONCLUSIONS & RECOMMENDATIONS

- There was no consensus on 'optimal time' to move to a care home – it is considered a highly subjective, personal decision, not necessarily related to symptom severity.
- Relatives felt enormous responsibility for making this decision on behalf of the person living with dementia and felt social services could have provided greater support regarding types of homes, but also regarding timing of the move and financing.
- Involvement of the person living with dementia in the decision to move appeared to influence better coping and adaptation (although numbers were very small); and many were keen to be involved if they could.
- Practitioners say they prioritise the wishes of the person living with dementia but at times their 'best interests' may over-ride this; almost all of these moves were thought to have resulted in positive outcomes.
- Social workers consider it their responsibility to weigh up different factors to advise/make decisions about the move of a person living with dementia to a care home; many struggled with balancing the needs of the person living with dementia and family carer/s.
- Self-funders have some scope for choosing timing of a move, and sometimes, but not always, choice of which home. However, many decisions occur at times of crisis or distress indicating that advance care planning remains under-developed in practice.
- Existing guidance and support about deciding whether and when to move to a care home are not widely known or recommended by practitioners; their existence should be more widely promoted at assessments and reviews of both people living with dementia and carers.
- Respite services and waiting lists offer welcome opportunities to consider a care home move before it is finalised; they should be part of early discussions about care planning.

COMMENT

"Presenting this study at our Professional Meeting was very interesting and generated considerable discussion.

"The study covers several reasons why 'optimal' time is not prescriptive and trying to identify the 'optimal time' to move to a care home is not easy. It opened up the debate as why the decision-making process can take time and there are occasions when one remains living at home while the family debate 'are they ready to move?' Sometimes they then admit with hindsight they may have moved earlier.

"As a General Manager, I can see that this study will open the dialogue about a move to a care home and this is helpful for people and staff introducing the topic".

Shaaron Caratella, General Manager,
Queen's Court Care Home, Barchester Homes
(10 May 2019)

REFERENCE

Cole L, Samsi K, Manthorpe J (2018) Is there an "optimal time" to move to a care home for a person with dementia? A systematic review of the literature, *International Psychogeriatrics*, pp. 1–22.
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