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'The time has come': reflections on the 'tipping point' in deciding on a care home move

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ABSTRACT

Objectives: Often perceived as a last resort, a care home move for a person living with dementia is often undertaken when all other options have been exhausted. Deciding the right or optimal time is to move remains an important question for many families. To investigate factors that are weighed up in deciding to make a care home move.

Method: Qualitative in-depth interviews with 21 family carers and 5 care home residents living with dementia in England. Thematic analysis was applied to all transcripts to extract key themes and sub-themes; a summation is provided here.

Results: Participants emotionally recollected an accumulation of stressors, exhausting other options of care, a risk/benefit analysis, wishes of person living with dementia, and a readiness to move as indicators of when a 'tipping point' was reached. They also felt strongly that early planning, prior experience of care homes, understanding funding arrangements and having support with decision-making would help.

Conclusion: Deciding to move to a care home is complex, contextual and deeply personal. Early planning in the form of joining waiting lists, using day centres and respite services may help in creating relationships with intended care homes for the future. There is growing need for support with financial advice and funding arrangements, for both self- and publicly funded individuals.

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Dementia;
care home move;
optimal timing;
qualitative

Introduction

Care homes have long been perceived as a 'last resort' for older people (Oldman & Quilgars, 1999) including people living with dementia (Chang et al., 2011; Caldwell et al., 2014; Lord et al., 2016). A move is frequently cloaked in negative terminology in the media, and in the practice and research literature (Cole et al., 2018). Across the developed world, people living with dementia in such circumstances are often described as passive, with words used such as 'placed' and 'abandoned' (Sandberg et al., 2001; Chang et al., 2011). Many older people, people living with dementia and the public fear moving to a care home (The Commission on Residential Care, 2014), yet there are over 5,500 care home providers in England and 410,000 residents (Competition and Markets Authority, 2017), with an estimated 70% having dementia (Alzheimer's Society, 2020). The Covid-19 pandemic has fuelled negative perceptions of care homes (amid high levels of sympathy for staff, residents and carers), with reports of a decline in care home moves in England, critical accounts of the care home sector being overlooked in access to equipment and testing, and alarming impacts on residents, staff and visitors (Comas-Herrera et al., 2020).

With increasing numbers of older people living with dementia and declining numbers of family carers, it is likely that care homes will continue to provide care, particularly for those with multiple long-term conditions and those at end of life. Thus, despite the pandemic and some market failures in England, deciding the right time (if any) to move to a care home will remain an important question for many individuals and families. Prior to the Covid-19 pandemic we conducted a study to address three research questions:

1. What factors in the decision-making process led to a person living with dementia moving to a care home?
2. What are decision-making roles of people living with dementia, carers or care home managers?
3. What do professionals advise carers and people living with dementia about an optimal time (if any) to move to a care home?

This paper presents findings responding to Research Questions 1 and 2 by sharing accounts from carers and care home residents living with dementia. Research Question 3 is the subject of another paper (Cole et al., 2020).

Methods

Following a systematic review of the literature (Cole et al., 2018), we identified paucity of data around decision-making about the 'optimal timing' for a move. A 'good' or smooth move was considered possible when both people living with dementia and carers were 'ready'; however, there was little suggestion how readiness could be conceptualised. Research often reported general unwillingness to move to a care home, suggesting that people living in care homes may have moved contrary to their wishes or when they were not able to make their views count (Chang et al., 2011). Our qualitative study investigated perspectives of residents living with dementia and carers in relation to timing of their move. The study was conducted in line with principles of rigour and trustworthiness, including credibility, authenticity, transferability, reflexivity and transparency (Williams et al., 2018). The present paper was

written using the COREQ checklist to ensure authentic and transparent reporting of qualitative research (Tong et al., 2007).

Study preparation and study advisory group

We prepared interview documents drawing on findings of our systematic review (Cole et al., 2018) and obtained ethical approval from the Health Research Authority Social Care Research Ethics Committee (16/IEC08/0035). Our data collection instruments were shaped by discussions with our Study Advisory Group at the first meeting prior to obtaining ethical approval.

The Study Advisory Group included 12 members from a range of backgrounds (care home management, policy experts, researchers, member of a leading dementia information and advice organisation, lay representatives who were current or former family carers). The Group met three times over the course of the three-year study and provided input and advice at key stages.

Sample

We recruited residents aged 65 and over, living with dementia, who had moved into a care home in the south of England in the previous 6-12 months, and their carer, through a variety of channels, using the techniques of purposeful sampling. We waited for a minimum of 6 months after a move to avoid causing undue distress amongst participants. We advertised the study amongst networks and worked actively with care homes which expressed interest in helping to connect us with eligible participants. Anyone interested was asked to contact the research team for further information.

Data collection

All interested and eligible participants were interviewed at mutually convenient times. All care home residents were interviewed at the care home, either in their own rooms or in common areas; and all carers were interviewed either in the care home, or in their own home. Interviews centred around circumstances around the move to the care home; decision-making processes involved; what helped, what hindered; what they might have done differently; and opinions about the timing of their move. We recorded all interviews with permission.

Ethical considerations

We followed ethical processes of obtaining informed consent prior to starting interviews, including informing participants of their right to withdraw or terminate the interview should they wish. We followed 'process consent' and being aware of non-verbal cues for any signs of wishing to stop the interview. These were especially important for residents living with dementia who may experience difficulties with verbally articulating feelings and concerns but may demonstrate their wishes through other cues (e.g. body language) (Samsi & Manthorpe, 2020). All participants had capacity to consent to participate. We conducted informal capacity assessments, following the 2-stage test of capacity as set out by the Mental Capacity Act 2005. A safeguarding protocol was in place in case we were told about or witnessed possible harm to residents, and a 'contact sheet' with useful numbers was available should any participant require it.

Data analysis

Interview recordings were transcribed verbatim and analysed using principles of thematic analysis (Braun & Clarke, 2020). Inductive analysis focused on identifying key trends or themes that related to factors or trigger points in the care home move. Initial line-by-line coding was conducted by KS on a randomly selected six transcripts. A coding framework was iteratively developed from these transcripts and was then applied to all transcripts. No specific between-group differences were identified between carers and residents; the same coding framework was therefore applied to both groups. When all data were coded, key themes were discussed within the study team. An overview of findings was presented to the Study Advisory Group for input and reflections. The research team was female, with backgrounds in gerontology, health and care research, and care home governance, each with over 10 years' experience in dementia and social care research. While this aided recruitment and data collection for the study, we were mindful during analysis to bracket our experiences and knowledge of extant literature and remain true to participant accounts.

Participant characteristics

We conducted 18 interviews with 21 carers (in 2 interviews, 2 carers were jointly caring for a relative with dementia), and with five residents living with dementia. Table 1 presents characteristics of carers, and Table 2 of participants living with dementia. Table 3 presents characteristics of people living with dementia who were not interviewed but whose circumstances were reported according to the carers interviewed.

Findings

We identified in participant transcripts the conceptual presence of a 'tipping point' or the point at which participants decided a care home move was necessary (Table 4 includes a full list of themes and sub-themes). For some, this 'tipping point' came about suddenly, such as while being discharged from hospital following treatment for injury in an accident or health crisis. For others, the 'tipping point' came as a more gradual realisation about the need for residential care. Other metaphorical statements used were 'feeling ready' and 'the time has come':

I suppose the thing that really was the tipping point was that she wandered off and one day she was down near the (major road) junction and a police lady brought her back. That made us think really the 'time has come'... I suppose we were a bit putting off the time, knowing it was going to happen. (Relative 01)

Table 1. Demographic characteristics of relatives.

Demographic characteristics	Number of relatives (<i>n</i> = 21)
Gender	
Female	12
Male	9
Ethnicity	
White	20
White Other	1
Relationship to person with dementia	
Adult child	15
Spouse	4
Sibling	1
Grandchild	1
Age in years	
Range (mean)	22–91 (60.29)

Table 2. Demographic characteristics of participants living with dementia.

Demographic characteristics	Number of participants living with dementia (n = 5)
Gender	
Female	2
Male	3
Age (years)	
Range (mean)	80–89 (82.6)
Ethnicity	
White	5
Time since move to care home (months)	
Range (mean)	3–7 (5.2)
Type of care home	
Residential	5
Location prior to moving to care home	
Home	5
Funding type	
Self-funded	5

Table 3. Demographic characteristics of people living with dementia (not participants) as reported by relative participants.

Demographic characteristics	Number (n = 18)
Time since move to care home (in months)	
Range (mean)	3–30 (9.42)
Missing data	6
Type of care home	
Residential home	14
Specialist dementia home	1
Not known	3
Location prior to moving to care home	
Home	12
Hospital	4
Not known	2
Funding type	
Self-funded	13
Local Authority	4
Not known	1

Theme 1: Emotionality of the experience

Interview narratives were suffused with emotion as all participants recounted their experiences of care home moves. Residents living with dementia were mostly equanimous about moves, with emotions ranging from resignation to acceptance. Carers were more emotional when recounting the decision and move. Several broke down crying during interviews but continued, keen to tell their stories so other carers did not go through what they had experienced. Many reported feelings of stress, frustration, and guilt in the period leading up to the move.

Several carers felt the full weight of responsibility to make the decision on behalf of their relative who had become unable to make the decision for themselves. Many said they ruminated on their decision long after the move, wondering if they had done the right thing and whether timing had been right. With hindsight, one carer reflected on the hastiness of their decision as things appeared to have 'reached a head' with the family not coping. Other options perhaps could have been considered with more forethought and less stress:

I think we panicked a bit. I think we could have, if it hadn't been for my sibling, I think we could have looked at other options... we did think about sheltered housing. But we realised that Mum had gone too far for that... For example, the daycare we had coming in, I think we should have done that sooner. (Relative 09)

Theme 2: Triggers

Where a care home move went relatively smoothly compared to the disruption or suddenness of a crisis, the reason was rarely a single incident, factor or 'trigger'. Often, a series of events or

Table 4. Themes and sub-themes and quotes.

Theme number	Themes	Sub-themes
Theme 1	Emotionality of the experience Triggers on the journey	
Theme 2		1. Accumulation of stressors 2. Exhausting other options of care 3. Wishes of person living with dementia 4. Risk/Benefit analysis 5. Readiness to move
Theme 3	What helped/hindered	1. Early planning 2. Prior experience of care home 3. Understanding funding arrangements 4. Support with decision-making

factors were recollected. We analyse some of these events to inform future learning.

1. Accumulation of stressors

Carers and people living with dementia felt they had coped for as long as possible before a care home move was considered. In many cases it was an accumulation of stressors that served as a trigger or resulted in a 'tipping point' when 'coping' began to fail. Such stressors included the carer realising the vulnerability of the person living with dementia to either physical, mental or financial harm after a series of incidents:

One day I came into the room and I saw her sitting there with her pills and she'd taken her pills again, after we'd given them to her for breakfast. And the next thing I knew, I was phoning the hospital saying, she's feeling very faint and going to have to take her into A&E. (Relative 17)

An accumulation of such 'near misses' led some carers to feel unable to continue to provide substantial care, and to be putting their own physical or mental health at risk. Some carers talked about juggling their own lives and commitments alongside caregiving responsibilities and recognising that this was becoming too much:

[Mum] used to get herself so upset and worked up that I was going to work and leaving her... The minute I went out of the door, she stood there with her coat on for an hour and a half waiting for somebody to come and pick her up [transport to day centre]. And then she used to get so stressed and really really upset. And yet... I am going to cry, sorry, I was in a 'Catch 22', I have to work. I have to work. (Relative 12)

2. Exhausting other options of care

Several carers described trying different types of regular support before considering a care home move. Typical sources of support that delayed a care home move were home care from the local authority or privately paid, moving closer to or in with family, and involving several family members to share the load of caregiving. However, it was recounted that even with all these sources of support, there sometimes came the 'tipping point' when more round-the-clock care was needed:

It was at that point where my brother and I just couldn't manage it [care at home] any longer. All of the contacts, everybody, we were organising their [parents, one of whom had dementia] money, their house, having the hedge cut, the boiler serviced, making sure they'd got dinners, taking them to appointments, just we were doing everything, all [parents] were doing were eating and sleeping. And we couldn't do it any longer... (Relative 16).

3. Wishes of person living with dementia to move

In a few cases, the person living with dementia indicated that they had been willing to move to a care home. While in

some cases these wishes were borne of other factors such as realising that support at home was not enough or that their needs were increasing, we specifically wanted to encapsulate the role of those living with dementia in the decision-making process and at what point they had deemed a 'tipping point' had been reached. This theme therefore reflected both an acceptance from people living with dementia of no longer being able to cope independently, as well as the recognition that their carers were struggling with supporting them, and that there was a need for 'back up':

Participant: Well, I just accepted it because I could see that we needed some help, we needed some family near us.

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

Participant: Well, back up. It wasn't physical help and it wasn't help to do with the housework or anything like that, but we felt that we needed somebody near us to back us up over things. (Person living with dementia 03).

One participant indicated being comforted by the idea of living in a care home with other people rather than being on their own:

It's comforting that there are people here should you, 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. (Person living with dementia 04).

Another resident recalled the pressures on his only child since the death of his wife and how that realisation had served as the 'tipping point' for deciding to move to a care home:

I think it is, because it does take a bit of the pressure off the main carer like [daughter] is to me. They [adult children] are under a lot of pressure. They are expected to be everything, to their offspring, parent, whatever. Some of them have got more than one dependent. (Person living with dementia 02).

Not all of these decisions were made without reluctance. Some carers described their family member living with dementia accepting the decision grudgingly, alongside some recognition that they were struggling to manage independently:

There were other things at home that, you know, she couldn't get out of the bath one day. ... the [care worker] found her sort of stuck in it and then the fire engine came because of the warden. They set off the smoke alarm, because the sausages were burning and things like that. We just sort of said, "look", we didn't give her a chance to say, "I am not going". I think she realised that she couldn't really say no. (Relative 01).

4. Risk/benefit analysis

The risks of living at home were continually being weighed up against the benefits of it, more by carers than by people living with dementia. Several carers described thresholds for what they felt were acceptable risks when living at home. When the risks outweighed the benefits, some carers described a 'tipping point' to have been reached when a care home move was deemed necessary. For example, this daughter carer described weighing up the harm from her father falling when out for a walk against the advantages of retaining his independence. When the risks seemed to be outweighing the benefits, the decision had tipped in favour of moving her father to a care home:

I wouldn't like to think that [my father] would have come in a year ago, because he still was walking, he still had an aspect of independence. That's clearly one of the things that you do lose coming in [to the care

home], he cannot go out on his own. I used to worry so much when he went out on his own, even though he knew the roads – it wasn't even about him getting lost, really. It was more about him falling or something like that. (Relative 05)

5. Readiness to move

Some carers and residents living with dementia reflected on the need to feel psychologically ready to move:

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. That is when I realised. (Relative 11)

'Readiness' was alluded to as a gut instinct, a feeling rather than tangible, observable factors. For example, this carer reflecting on whether the timing had been right for her sister's move, described weighing up the benefits of retaining her autonomy despite the financial risks she was taking:

She was not ready [then] to come into a (care)home. She used to still go out to the shop and get her (news)paper and do all that. Okay, used to leave her credit card all over the place! [laughs] But [later] I think it was the right time for her to go into a (care)home. (Relative 01)

In some cases, readiness was described as a shared concept, experienced by the whole family when they concluded that 'we are not ready yet' (Relative 10).

Theme 3: What helped or hindered

While deciding about a care home move, participants described factors that helped or hindered decision-making.

Early planning

Early discussions about the eventuality of moving to a care home were remembered as helpful. Several carers and three residents living with dementia described being prepared for a move. One carer who had been supporting her sister with dementia said that with the diagnosis of dementia, both had a shared tacit understanding that a care home move was probably inevitable:

We'd always felt that this was probably what was going to happen in the natural course of the dementia. I know there are people that look after their relations at home and they are marvellous, but we knew with [sister] that this would be the outcome when she got to a certain stage. (Relative 01).

One participant living with dementia reflected on this as 'facing up to the fact':

You've got to face up to the fact, as one gets older, that you can't do things that you used to do. So you've got to go into a care home and er, be looked after, yeah. You've got to be, be a realist. (Person living with dementia 05)

Some people living with dementia and carers had put their names on waiting lists for local care homes so that, when the time came, they would not be left waiting for a vacancy at the care home they wanted. One carer had been encouraged by the care home to do so:

I think, you know, when we first went to [name of care home] they said, if you put your name down and a place comes up and you don't want it then we just offer it to the next person on the waiting list. Whereas if you were at the bottom of the waiting list and you are then in a crisis, it's too late sort of thing. (Relative 10)

Prior experience or knowledge of care home

Many participants recounted that prior knowledge or experience of care homes helped their decision-making. This familiarity was often as a result of another family member having lived in the same care home, or knowing about the home's local reputation. Some had closer experiences of having used facilities offered by the care home, including a brief residential respite stay or regular day centre attendance:

She started going to care home for (two or three episodes of) respite first of all. She was aware of the staff in the (care)home and the (care) home before she moved in. It was really a combination of her dementia [getting worse] and my own and my partner's health problems that helped decide when was the right time. ... we wanted the respite to be where she was going and we wanted her to know where she was going. She wanted to know where she was going. (Relative 10)

Understanding funding arrangements

There was limited understanding amongst participants about payment responsibilities at the time of the decision. Many carers recounted how deeply frustrating they found not having anywhere to turn for information about paying care home fees and funding arrangements, especially regarding payments, entitlements, and how long one's savings would last and what would happen when savings ran out. Disappointment was expressed about the lack of support from the local authority, especially by those who were paying their own fees. This group of 'self-funders' said social workers gave them a list of care homes and directed them to the Care Quality Commission (CQC – the regulator of care homes) website to choose a care home but no further guidance or advice was offered. As previously described, sometimes savings ran out but support and advice about next steps were not always available, compounding anxiety:

I suppose the financial bit has been quite difficult trying to work it all out. That has all been quite stressful actually, because we didn't know, with them [health and social care practitioners] saying, one saying she's going home and the other saying, she can't and everything. It meant that her house was empty for almost a year, because we couldn't sell it because she might be going home. And that was all very difficult. (Relative 04)

Amongst residents living with dementia, most appeared to have left the funding arrangements and financial decision-making to other members of the family:

It was not as though, thanks to [daughter], we had no other pressures like lack of money, you know, finances or anything like that. As I said earlier, she is a very clever person, she is a very clever girl. She has done this and bought her house and what have you. (Person living with dementia 02)

Support with decision-making

The decision-making process and move seemed much easier with family consensus and support. A resident reported that reaching a consensus about the decision with the wider family was invaluable:

I've got very good support from my children who are all in their 50s now. So that was, you know, that was good and my eldest daughter has Power of Attorney and things. Sort of a shared decision. (Relative 01)

There were nuances of family support, however, with not everyone necessarily in agreement with the timing of the move or the actual decision:

My elder brother thought it was something that could be put off and we could perhaps do other things like getting in more care. But my sister just, she just had got to the end of her tether, really with phone calls and things. (Relative 09)

Many carers talked about the lack of support they encountered when needing to find a care home, and being passed from 'pillar to post' (Relative 09). One carer was tearful as she recounted the stress with navigating the learning curve with finding all the information on her own with no help from services:

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)

For some, support came in the unexpected form of the care home manager, who offered carers of potential residents their time, detailed information, and for some much-needed reassurance and advice.

Discussion

This study has identified the complex, contextual and deeply personal reasons considered by residents living with dementia and their carers/families when deciding an optimal time for a care home move.

Several studies from different countries have explored what constitutes a 'tipping point' (Butcher et al., 2001; Crawford et al., 2015; Lord et al., 2016) to a care home move. A recently published Australian paper using the same metaphor (McGrath et al., 2021) identifies similar trajectories but stops short of identifying tipping points within the themes identified. Our participant narratives indicated use of these and other similar phrases; however, we have taken this metaphor further to elucidate what are the time- or place-dependent contextual factors that determine when a tipping point may be reached, prior to a care home move. Participants' reflections on weighing up various factors resulted in them deciding whether a care home move was necessary at a particular time, including the need to take account of vacancies in a preferred home, and is a topic that has not been considered in previous studies. Awareness of these tipping points can alert social care practitioners, carers and people living with dementia to early and growing signs of stress and when an intervention could prevent a tipping point becoming a crisis.

Early planning for a care home move may be socially and professionally disapproved of and, whether the person living with dementia wants to or not, does not appear to be generally discussed, leaving carers responsible for embarking on such discussions themselves. We do not know the content of discussions with professionals post-diagnosis and whether people are advised about, for example, joining a waiting list for a care home place (Caldwell et al., 2014). Using day centres within care homes and taking up respite services might be useful in creating a relationship with an acceptable care home. However, in the context of the Covid-19 pandemic and its possible legacy, such relationship building may be more difficult.

Carers and some participants living with dementia were actively making positive risk-taking choices. A widely promoted definition of 'positive risk-taking' (Manthorpe & Moriarty, 2010) encourages professionals to look beyond physical harm and to weigh up the impact on well-being or self-identity of the person deemed to be at risk. By weighing up the benefits of staying in their own homes for as long as possible against the risk of harms, carers were ultimately deciding whether the risk was worth taking (Lord et al., 2016).

Our study indicates how limited support with financial planning affects both self-funders and local authority funded

residents. Many carers, even when moves were planned, had limited understanding of funding arrangements, payments and entitlements, leading to high levels of distress and anxiety, especially when savings started to run out. Our interviews with care home managers painted a picture of their key role in informing potential residents and their families of payment arrangements (Cole et al., 2020). Studies following the Care Act 2014 (Manthorpe & Martineau, 2016) have shown that information is variable and often not comprehensive, despite local authority obligations to offer this. Any reform of the financial contributions to care home payments in England should ensure that advice and information are clear and accessible, as personally tailored advice results in confident and less worried consumers (Himawan, 2020).

This study could help inform dementia care decisions in the post-Covid-19 context in other countries with residential care provision. It has provided evidence that carers often explore different options to help the person living with dementia stay at home but for some these become no longer tenable. These options may differ in a Covid-19 pandemic context as home care and day centres have been less available (Giebel et al., 2020) but seem likely to re-emerge as key supports for people living with dementia and their carers.

Limitations

This study was limited by having more accounts from carers than residents living with dementia, and from timing of interviews which covered decisions made some time previously. The sample was almost wholly White British, save for one participant, and most were female. The strengths of the study lie in the richness of participant narratives and recollections of the move and its context. We were able to talk with carers whose care home fees were self-funded, as well as some carers whose family members' care home fees were being met by the local authority.

Conclusion

This paper contributes to growing evidence that carers and people living with dementia often postpone the decision to move into a care home, until a crisis or tipping point is reached. While in some cases this tipping point may be precipitated by the availability of a preferred care home having a vacancy, rarely were these decisions or moves made with foresight or in a planned manner. Supporting carers and people living with dementia to have these discussions in advance of reaching a 'tipping point' can have long-term implications for quality of life for both groups.

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