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Research Article

Could Peer-Mentors Support Families of Care Home Residents to Prepare for Deterioration and End-of-Life? An Interview Study with Families and Care Home Staff

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When older people move into a care home, family members often continue to be involved in caregiving. This can include contributing to discussion and decisions about care and treatment, especially when the resident lacks capacity. However, families may not know what to expect as their relative's condition progresses and may not have a good understanding of their relative's end-of-life care and treatment wishes. Therefore, although often willing, families may feel unprepared for making decisions in advance of or at the time of deterioration and end-of-life. The study aimed to explore the potential role that peer-mentors might have in supporting families to prepare for discussion and decisions about care and treatment and to understand what participants would consider to be important characteristics of an effective peer-mentor and peer-mentoring program. The study was guided by the philosophical assumptions of social constructionism. Data from semistructured interviews with 14 current and 15 bereaved family members and 11 senior members of care were analysed thematically. Findings suggest that peer-mentors could help to empower families to prepare to be involved in discussions and decisions about the types of care their relatives might receive as their health deteriorates and they reach the end-of-life. However, it was seen as important that peer-mentors have lived experience of supporting a relative in a care home, strong interpersonal and communication skills, and the ability to discuss deterioration and end-of-life in a compassionate but factual manner. Although peer-mentoring is often time-limited, introducing mentors to families earlier in the care journey, for example, before admission into a care home, could enable a trusting relationship to develop. This, in turn, could facilitate open discussions about what to expect and different care choices as the person's health changes.

1. Introduction

Older people often move into a care home due to deteriorating health, frailty, and/or cognitive impairment. A move into a care home is a complex decision, influenced in part by the ability of family members (within this study, the term "family" is used to refer to individuals who are important to the person living in a care home and who support their care; this may include relatives such as spouses and children but can also include "chosen family" such as close friends or alternative family forms) to provide informal care at home [1, 2]. The move to a care home does not negate family members' desire to remain involved in their relative's care and to contribute to decisions about care and treatment [3]. Family members may take on the role of an "advocate" or "spokesperson," considering what might be in their relative's best interest, especially when the person has dementia and/or other conditions that affect their ability to be involved in decision-making [4–6].

People who live in care homes have significantly shorter life expectancies than age-matched people living in the community [7]. The prevalence of dementia is high in care

homes: over 80% of residents have some form of memory impairment [8]. Therefore, a move into a care home might be suggestive of a need to prepare for potential future deteriorations in health and the end-of-life. Research involving care home residents with varying degrees of cognitive ability (including those with a diagnosis of dementia) has suggested that care home residents are willing to discuss end-of-life and dying [9]. However, in practice, families may also be involved in discussions and decisions about how and what types of care may be provided at these times.

Families may not have a good understanding of their relative's wishes and preferences with regards to end-of-life care and treatment [10], which can lead to feelings of uncertainty [11] and experiences of stress, anger, regret, and guilt [12, 13]. Family members may not know what to expect as their relative's condition deteriorates and, although willing, may be unprepared to be involved in decisions about end-of-life care. Therefore, supporting families to prepare for future discussions around changes in their relative's health could improve residents' and family experiences including of dying.

The process of documenting and recording discussions about a person's wishes regarding future care and treatment is often referred to as advance care planning. In many countries, including the UK, national policy suggests advance care planning can improve end-of-life care [14, 15]. However, planning for deterioration and end-of-life when a person has dementia can be especially difficult, as many people do not recognise dementia to be a terminal condition [16, 17]. Despite these difficulties, advance care planning has been found to be beneficial for both older people living with dementia, increasing concordance between people's wishes and the care they receive [18].

In care homes, advance care planning provides residents, families, and staff with an opportunity to anticipate a resident's needs prior to deterioration and to create a written plan to guide "in-the-moment" decision-making. This in turn can reduce conflict at the time of deterioration and legitimise decisions not to transfer a resident to hospital [19]. This is important because hospital transfers and admissions can be burdensome for older people, particularly those living with cognitive impairment and frailty [20, 21]. However, creating an advance care plan is not a guarantee to ensure families feel prepared to be involved in decisions about deterioration and the end-of-life. Therefore, conversations about deterioration and end-of-life care should be ongoing [19, 22, 23].

This study was conducted in order to inform a wider body of work, which aims to develop a complex intervention to empower family members of care home residents to think ahead and prepare to be involved in discussions and decisions about deterioration and the end-of-life. The study was developed in consultation with families of older people who live in care homes; they told us about a lack of support and advice available to enable families to prepare for discussions about deterioration and the end-of-life. Many people said they would have liked support from someone who had been through a similar experience to themselves. Family members also expressed an interest in offering support to others on the same journey, so others may avoid their difficult experiences. This type of support is often referred as peer-support or peer-mentoring.

Often, terms such as peer-support, peer-mentoring, befriending, and volunteer-mentoring are used interchangeably [24]. Within this study, the term peer-support is used to refer to help from someone who has been through similar experiences [25]. Peer-mentoring, is conceptualised as a particular type of peer-support that has been defined by Townsend [26] as support from someone "*who has successfully faced specific experiences and provides empathic understanding to another person, helping that person adjust to a similar experience*". In comparison to peer-support, peer-mentoring is more structured, time-limited, and goal-focussed. Although the person allocated as a mentor may benefit from undertaking this role [24, 27, 28], the focus is on supporting the mentee, rather than in the reciprocal support exchanged in other forms of peer-support.

The benefits of peer-support for people living with dementia have been highlighted in policy and guidance documents [25, 29]. Peer-support is beneficial for people who support a family member living with dementia at home [25, 30–32]. To date, research has neglected to consider whether different forms of peer-support may be beneficial for people who support a person living in a care home, where decisions about deterioration and dying can be complex and influenced by numerous actors and the care home's policies and informal norms [33, 34]. Furthermore, little is known about whether more formal peer-mentors might be useful in helping families to prepare for discussion and decisions about end-of-life care. In order to address gaps in the current evidence base, this paper is led by the primary research question: "what role (if any) is there for peer-mentoring to be used to support families of people in care homes who lack capacity, particularly around preparing for discussions and decisions as their relative's health deteriorates?"

In line with guidance on developing and evaluating complex interventions [35–37], the aim of the study was to conduct primary research with current and bereaved family members of care home residents and senior members of care home staff to explore their views regarding the potential for peer-mentors to support family members to prepare for future deteriorations and the end-of-life. This evidence will be used to develop future interventions, identify outcome measures, and evaluate the effectiveness of a future intervention. The findings will also feed into a theory of change regarding the mechanisms by which a potential future intervention may be effective and the context required for it to be successful.

2. Methods

The study has been reported in line with the Standards for Reporting Qualitative Research (SRQR) [38].

2.1. Research Question and Aims. The aim of the study was to explore the potential role that peer-mentoring might have in supporting family members of care home residents to

prepare for discussion and decisions about care and treatment as their relative's health deteriorates. In doing so, a further aim of the study was to understand what families and care home staff would consider to be important characteristics of an effective peer-mentor and peer-mentoring program.

2.2. Study Design. This qualitative study was guided by the philosophical assumptions of social constructionism, which suggests culture and past experiences shape a person's understanding of an experience [39]. Rather than seeking to identify descriptions of a static, external "reality," the constructivist approach to qualitative research acknowledges that what is "true" may be subjective and different participants may offer different accounts of "reality" [39–41]. Thus, a constructivist approach allowed for different participants to describe different, and at times, competing experiences, of supporting a relative in a care home and for diverging views on the potential uses for peer-mentoring to be used to provide support for family members to be presented [41].

2.3. Ethics. Ethical approval was obtained from the University of Leicester's Research Ethics Committee for Medicine and Biological Sciences (Reference: 32446).

2.4. Target Populations. Three populations were targeted during this study. To participate in the study, individuals had to either be

  (i) A current family member of a person living in care home who, due to dementia and/or other illnesses, was unable to contribute to discussions and decisions about their care and treatment as their health deteriorates.

 (ii) A bereaved family member (bereaved in the last 3–36 months) of a person living in a care home who, due to dementia and/or other illnesses, was unable to contribute to discussions and decisions about their care and treatment as their health deteriorates.

(iii) A senior member of staff working in a care home in Leicester, Leicestershire or Rutland. Seniority was determined either by formal job title (for example, a manager and a deputy manager) or by the leading role that individuals had in supporting residents and their family members at times of deterioration.

2.5. Sampling. The research team aimed to recruit family members who were of different ages, ethnicities, and genders; had been caring for their relative for different periods of time; and who had different familial relationships with the person residing in a care home (for example, a spouse, parent, or sibling). Therefore, the study was advertised widely. Potential family member participants self-identified themselves by expressing an interest in the study by contacting the LOROS research team by email or telephone. Therefore, an opportunity sampling approach was used; however, the research team also incorporated a purposive

sampling of respondents to maximise diversity in the demographic characteristics and experiences of participants.

Potential care home staff participants were identified by a member of the research team approaching care homes directly. At the outset of the study, it was not known which characteristics of care homes (if any) would influence family member experiences of supporting their relative at times of deterioration and their perceptions of peer-mentoring or staff experiences of supporting families at times of deterioration and the end-of-life. Therefore, a purposive approach to sampling was adopted based on publicly available data about whether or not the home offered nursing services, the size of the home (determined by the number of beds), the size of the provider (determined by the number of homes), and the Care Quality Commission rating. During data collection, the research team sought to explore additional characteristics which might influence family members' experiences of supporting a relative during deterioration and the end-of-life and staff experiences of supporting families during these occasions. Sampling of care homes was an iterative process. For example, at later stages of the study, the research team deliberately sought out a care home that advertised itself as catering for people from a South Asian background and a care home that advertised itself as being able to provide specialist care for people with a range of different religious faiths.

2.6. Recruitment. The study was advertised online via social media platforms, LOROS (the Leicestershire and Rutland Organisation for the Relief of Suffering) hospice's communication channels, the research team, and the stakeholder group members' contacts. Posters were also placed in local care homes in communal areas where families were likely to see them. Once people expressed an interest in the study, a member of the research team contacted the potential participant to confirm eligibility criteria. People who were eligible to participate were posted or emailed a study information sheet. Follow-up contact was made to address further questions. If potential participants did not respond to two research team contacts, they were considered not wanting to participate.

2.7. Data Collection. Semistructured interviews were conducted between March 2022 and April 2023. Interviews with family members took place face-to-face in either the participant's home or the researcher's workplace, or virtually via Microsoft Teams©. Interviews with care home staff took place face-to-face in the participant's workplace. Each interview was audio-recorded and transcribed verbatim. All identifiable data were removed during transcription, and each participant was given a participant number.

Three interview schedules—for current family members, bereaved family members, and care home staff—were developed through a review of existing literature and through stakeholder engagement (see supplementary files 1–3). Interview schedules for current and bereaved family members included questions about their experiences of supporting a relative living in a care home and their views about whether

peer-mentoring may have a role in supporting families to prepare for deterioration and the end-of-life. The interview schedule for bereaved family members included additional questions about participants' experiences of supporting a relative at the end-of-life. The interview schedule for care home staff included questions about staff experiences of working with families—both generally while a person was living in the care home and specifically at times of deterioration and the end-of-life—and about the potential for peer-mentors to support families of people who live in care homes.

2.8. Analysis. Data were analysed thematically to generate contextualised themes [42–44]. There are a number of different approaches to undertake thematic analysis which can be applied across a range of epistemological approaches [44]. In the current paper, a constructivist thematic analysis was conducted. Analysis was an inductive and iterative process, occurring alongside data collection. In line with recommendations from Braun and Clarke [42–45], each transcript was printed to allow the authors to familiarise themselves with the data. Each transcript was hand-coded on a line-by-line basis according to the phenomenon or concept that was being discussed. Initial codes were inputted into computer software programs to enable sharing amongst the research team. The two datasets (one for care home staff and another for current and bereaved family members) were initially treated as separate datasets. Initially, one author (FHH) led analysis of data relating to family and bereaved carers, and another author led analysis of data relating to care home staff (SA). A third member of the research team (LB) independently coded a small number of transcripts across both datasets.

Summaries of each dataset were created and discussed amongst the team. Following the identification of initial codes, both datasets were brought together, and through a process of constant comparison, the research team identified similarities and differences within and across the data sources. This process of triangulation enhanced the trustworthiness of findings [46] and enabled the identification, review, and naming of themes and subthemes. To enhance reflexivity, emerging interpretations were discussed and challenged within the wider research team and two stakeholder groups. This added to the dependability of interpretation and provided new directions along which the researchers could look [47]. Data were collected until theoretical saturation was achieved. Theoretical saturation was judged to be the point at which the research team agreed that no new themes were likely to emerge from subsequent data collection.

2.9. Stakeholder Engagement. Two stakeholder groups supported all stages of the research, helping to develop study materials, review recruitment, and discuss the analysis and findings. The first group—the public involvement group—was made up of nine people with lived experience of supporting a family member with dementia in a care home. Several were members of local groups that support family carers. The group, chaired by GJ, met five times during the

study. The second group—the Carer Matters stakeholder group—consisted of bereaved family carers, comissioners and representatives of local carer groups and organisations across the East Midlands. Five meetings were held during the study.

3. Findings

Forty-three family members expressed an interest in taking part. Five people were ineligible to participate. One person had been bereaved for more than 36 months, and two people had supported a relative who had spent time in an acute or mental health hospital rather than in a care home. A further person was not recruited because the study was over-recruited for bereaved family members, and another person who had a professional background in health was not recruited because the sample already had sufficient representation of people with this characteristic. In addition to the five people who were ineligible to participate, nine did not respond to follow-up contacts. Therefore, twenty-nine family members were recruited.

Sixteen care homes were approached. Five homes either declined to participate or did not respond to the research team after being contacted three times. Eleven senior members of care home staff were recruited, each from a different care home. Therefore, in total, interviews were conducted with 40 participants. This included 14 current family members, 15 bereaved family members, and 11 senior members of care home staff. All family member participants had experience of supporting a relative living in a care home who had limited abilities in discussing their own care and treatment. All but five family members supported a person living with dementia. The remaining five family members supported a person who had cognitive impairments due to a stroke (3 people), acquired brain injury (1 person), or global developmental delay (1 person).

Interviews with family members lasted between 45 and 85 minutes (averaging 63 minutes), and interviews with care home staff lasted between 45 and 95 minutes (averaging 51 minutes). Information about family member participants is shown in Table 1. Information about care home staff participants and the care homes they worked in is shown in Table 2. While the findings of this paper present data related to all three participant groups, bereaved families and care home staff were more likely to have concrete experiences of providing support at times of deterioration and at the end-of-life to draw on than current family members.

The findings are presented below through three core themes:

(1) Components of support for family members—outlining participant thoughts on the types of support family members may need

(2) Considerations on peer-mentors as a form of support—describing views on the degree to which a peer-mentor may support a family member at times of deterioration, the types of support they could offer, and the characteristics of an effective peer-mentor

TABLE 1: Demographic characteristics of family member participants.

Variables	n	%	Mean	Range
Status				
Current family member	14	48		
Bereaved family member	15	52		
Age (years)			57.51	27–91
20–30	1	3		
31–40	1	3		
41–50	7	24		
51–60	11	38		
61–70	4	14		
71–80	3	10		
81–90	1	3		
91–100	1	3		
Gender				
Female	23	79		
Male	6	21		
Ethnicity				
White British	21	72		
Asian British	3	10		
White Irish	2	7		
Mixed White and Asian	1	3		
Mixed Chinese	1	3		
Any mixed other	1	3		
Caring for				
Parent/parent-in-law	19	65		
Spouse	5	17		
Others	5	17		

TABLE 2: Demographic characteristics of care home staff participants and the care homes in which they were employed.

Variables	n	%	Mean	Range
Home demographics				
Home type				
Residential home (care home without nursing)	7	64		
Nursing home (care home with nursing)	4	36		
Beds			48.36	12–73
Fewer than 30	1	9		
30–50	6	55		
50 +	4	36		
Care quality commission rating				
Outstanding	1	9		
Good	8	72		
Requires improvement	2	18		
Participant demographics				
Age (years)			43.90	25–60
20–30	1	9		
31–40	4	36		
41–50	3	27		
51–60	3	27		
Gender				
Female	10	91		
Male	1	9		
Ethnicity				
White British	5	45		
Indian	3	27		
White Irish	1	9		
White other	1	9		
Asian British	1	9		
Time in current role (years)			2.75	0–5

Variables	n	%	Mean	Range
Less than 1 year	3	27		
1–3	6	55		
3–5	2	18		
Time in care sector (years)			15.45	3–25
Fewer than 10	2	18		
10–20	6	55		
More than 20	3	27		

(3) Concerns and caveats—raised by participants that would need to be considered before developing a peer-mentoring program

3.1. Components of Support for Family Members. Approximately half of the family member participants reported they had received peer-support. This most often occurred in a group format but also occasionally occurred on a one-to-one basis, when participants knew friends and colleagues who had experience of supporting a relative in a care home. Although none of the family members believed their prior experiences fit the definition of peer-mentoring, participants talked positively about peer-support they had received. Three people said that the peer-support they received overlapped with peer-mentoring.

"That's definitely what happens because people talk to each other. You've got a resource of different experiences at your fingertips when you go to the group. You don't usually find one person to talk to and learn from, you learn from all, because every experience is different. (Bereaved Family Member 04)"

Despite lack of experience, the majority said peer-mentoring would be beneficial for families of people living in care homes. All care home staff participants were positive about the potential for peer-mentoring to support family members.

"It would be a very good idea to have something in that gap, because it's an overwhelming time... I personally would have valued it a lot. It would be very helpful to a lot of people; a balance of emotional and practical support is really what you need. (Bereaved Family Member 03)"

Throughout the interviews, several participants used the same language as Bereaved Family Member 03 (above) describing a need for both "emotional" and "practical" support. When talking about the practical support peer-mentors could offer, participants suggested peer-mentors could help families to understand and navigate health and care systems and to plan for issues that may occur as the person moved towards the end of their life. When talking about types of emotional support peer-mentors could offer,

participants described opportunities to talk about their experiences and how they had been affected by them.

"Going back to the practical side – someone who knows what's ahead of you... helping you to think about some of those things that might be coming up, because, well certainly for me, that helps you feel a little bit more in control! (Bereaved Family Member 06)"

"Let me just talk and express those feelings and just be there, potentially with a bit of information along the way. But to just allow that time...with somebody that doesn't mind and has got time to do it, because I felt guilty about taking up people's time and everything. But knowing that was allowed would be helpful. (Bereaved Family Member 09)"

Therefore, although the participants lacked experience of peer-mentoring, it was clear that they considered themselves as having unmet emotional and practical needs, for which peer-mentors could potentially provide support.

3.2. Consideration on Peer-Mentors as a Form of Support. With regards to whether peer-mentors could support families to prepare for decisions and discussions about deterioration and the end-of-life, participants provided mixed responses. On the one hand, some said talking to a peer-mentor could enable families to have open conversations that normalise discussions about deterioration.

"As a carer you may not be quite ready to have those discussions. Good peer-support could help to pave that way... so that you appreciate that this is normal and it doesn't mean that your relative's going to die instantly or anything like that. (Bereaved Family Member 02)"

Peer-mentors might also help families acknowledge the possibility that the person could continue to deteriorate and reach the end-of-life.

"I would (have liked to have acknowledged the possibility that they might not get better), yeah, because it was always in my head as an option if you like, as a possibility, but I was never really allowed to say it. (Bereaved Family Member 03)"

On the other hand, two participants suggested families might not feel comfortable discussing the end-of-life with a peer-mentor. One person talked of a fear of discussing and acknowledging the future death of possible death of their relative:

"(Interviewer: Would you have felt comfortable to have that conversation or not?) Um…even though I knew it was coming, no I don't think I would want to, which is weird… I think I was scared more than anything. (Bereaved Family Member 07)"

*"Another participant spoke of the private nature of end-of-life and was concerned a peer-mentor might be perceived by families as intruding during a sensitive time. For a lot of families, that time around en*d-of-life is *very private and they don't want to be disturbed… They may not want people to interfere. It is a delicate time, a sensitive time. (Care Home Staff 07)"*

Five participants said they were unsure whether peer-mentors had a role in supporting families at times of deterioration or the end-of-life. One person gave mixed responses within the same interview. For example, during an earlier part of an interview, Bereaved Family Member 08 stated as follows:

"I think it would work. I mean I would have liked to have been more prepared to be honest. I would have liked to have talked about it."

However, later in the same interview, the same participant stated as follows:

"I don't think I would have (wanted to talk to a peer-mentor). I think it would have upset me to talk about it to be honest."

Many participants described a preference for developing a relationship with a peer-mentor early in the care journey. Most frequently, participants suggested that they would have liked support at the time they were seeking a care home. By developing a relationship with a peer-mentor earlier in the journey, participants suggested they would be more likely to feel open to discussing deterioration and potential end-of-life situations.

"I would have been open to a discussion if they were going to include other things along that journey, along that pathway that leads up to end-of-life. If they're able to explain how they're going to deteriorate… that would have been helpful. (Bereaved Family Member 04)"

Participants highlighted the need to time conversation appropriately. Both family and staff suggested that the "right" time to discuss deterioration and the end-of-life would be variable, based on the willingness of family members of having a discussion and the health status of the person. Although staff highlighted the importance of understanding a person's wishes related to the end-of-life on admission, particularly if their health was unstable, they also recognised that admission could be an emotionally difficult time for families.

"Normally we start to talk about (end-of-life) on admission, it doesn't always happen like that though… It's not always the greatest time because families are already upset about moving in. It can be a little bit insensitive to then say "by the way what are your thoughts on end-of-life?". (Care Home Staff 01)"

When asked about potential topics that families might discuss with a peer-mentor, participants identified a range of questions and issues that related to all stages of the care journey. Participants suggested that families might discuss how to find an appropriate care home, what level of care a care home can be expected to provide, and information on dementia and how it may progress over time. Many issues were identified specifically related to the end-of-life, including how to recognise a person who may be approaching the end-of-life or dying, how to determine if someone is uncomfortable or in pain, and what to expect in terms of the physical changes to the body.

When asked about what might be considered important characteristics of a "good" or "effective" peer-mentor, almost all participants, across family members and care home staff, talked about the need to recruit the "right" kind of people to the peer-mentor role. When probed further about what qualities the "right" people may have, participants talked about the importance of having lived experiences of supporting a relative in a care home.

"You don't want someone who just quotes something out of a book … We've read the leaflets and books (and) we know in theory what we should and shouldn't do… It doesn't always work. I think it has to be someone who's got some first-hand knowledge. (Bereaved Family Member 04)"

Participants also talked about the importance of peer-mentors having strong interpersonal and communication skills, including the ability to be able to discuss deterioration and the end-of-life in a compassionate but factual manner.

"You've got to be very sensitive, compassionate, empathetic… Be factual but be truthful… You can't sugar-coat what's going to happen… But it's the way that you put it across that makes the difference. (Care Home Staff 02)"

Furthermore, when asked about what a "good" or "effective" peer-mentoring program might offer, several participants talked about the need to create the right atmosphere, with an appropriate level of (in)formality. This was also a topic of conversation amongst the stakeholder groups throughout the study.

"I don't want people to be unprofessional, but to see it as a friend thing rather than a medical thing… Informality is perhaps the word I'm thinking… There are enough

professionals (involved), enough doctors, enough people telling you what to do... Something a bit less formal I would find more helpful. (Bereaved Family Member 13)"

Finally, participants suggested that an effective peer-mentor might "ease the transition" into a care home (Bereaved Family Member 01) in a number of ways. This included by allowing families a space to discuss their concerns and express their feelings, acting as a source of support and advice, helping families to navigate health and social care systems, and helping families by pre-empting issues that may occur as the person moves towards the end-of-life.

The findings presented above suggest that in order to develop a model of peer-mentoring for families of care home residents, it would be important to consider whether families might prefer support earlier in the journey (for example, during the transition into a care home) and whether families would want involvement from a peer-mentor at the end-of-life. It would also be important to consider the need to recruit people with good interpersonal and communication skills and lived experience of supporting a relative in a care home and to create an appropriate atmosphere in which people felt comfortable to discuss a range of topics.

3.3. *Concerns and Caveats.* There was great diversity amongst the experiences of family participants in response to questions about whether they might prefer to work with a peer-mentor with particular demographic characteristics (such as age, ethnicity, background, or relationship to the person in care), and the majority of participants explained that although the specific circumstances of their situation were individualised, there were often similarities across experiences of people supporting a relative, and therefore, they would be able to find commonality even when another person's situation was different to their own.

"All our relationships (with the person living in the care home) are different, but there are things that puncture that journey that you go "ah I know exactly what you're talking about." And if you talk about it, you know, if you give a different perspective, it can really help. (Bereaved Family Member 14)"

"Every case is different, obviously every experience is different, but the core of it is still the same. (Care Home Staff 11)"

Although the majority of participants said that they would not need to be matched with a peer-mentor, a minority of participants offered a divergent perspective. This was particularly true for participants who had distinct experiences. For example, one participant said they would prefer to be paired with someone who, like them, had experience of juggling employment alongside caring responsibilities for both an older relative and young children.

"I think I'd benefit from that support, particularly if there's someone else in my situation who is younger, with a young family and working and all of the different impacts that

that brings... it's kind of quite a niche area, isn't it? (Family Member 03)"

Another participant spoke of a preference for being paired with someone who "looked like them," with whom they had a shared cultural background.

"I think you need that shared background... somebody that kind of understood at least some of the cultural norms, that would have been helpful... somebody who represents me or who looks like me... Like I said, I wasn't your typical carer. (Bereaved Family Member 05)"

Participants described various formats peer-mentoring could take. This included one-to-one or in a group and face-to-face or via telephone or video call. The majority of participants acknowledged that preferences would vary across individuals. For example, in the extract below, the participants suggest that support that is delivered virtually and on a one-to-one basis would be preferable. Like this participant, some participants discussed one-to-one support as more personal and less intimidating than a group setting. In particular, like participants referred to supporting a relative during deteriorations, as a "vulnerable" time for them as a relative.

"(I feel) nice and secure behind a phone or through a videocall, because it's such a vulnerable time... I don't think a group would have worked for me. (Bereaved Family Member 13)"

On the other hand, other participants said that attending an in-person group peer-mentoring session may feel less intimidating that a one-to-one session, as there would be less pressure to both participate in the group and form a relationship with the peer-mentor. Furthermore, participants suggested that attending a group session would enable them to have discussions and draw up the experiences of several people, which might not be possible in a one-to-one session.

"My absolute nightmare would be having a peer-mentor who I just thought "well I don't like you!." If you put people in a group, you kind of gravitate towards certain people.... it takes the pressure off because you could listen to a variety of stories that you might connect with... a more collective supportive environment. I personally would have preferred something like that. (Family Member, 14)"

Although people were generally positive, suggesting peer-mentors could have a potential role in supporting families to prepare for discussions and decision about deterioration and the end-of-life, two participants suggested that they would not have felt the need to seek out a peer-mentor because they had access to support or health and social care expertise within their own social networks.

"No, I wouldn't have (approached a peer-mentor). You see, my sister, a couple of her friends are GPs, so we've got sources to pull that information, we are getting more

support than some people who have not got a professional background. (Family Member 02)"

Two members of care home staff raised concerns about the potential difficulties in engaging with families. They suggested that families may not want to engage due to a desire to maintain their privacy or due to the difficulties in finding time amongst competing pressures.

"I suppose it's just trying to get people involved. That's what I find difficult... trying to get the families involved - because of time constraints and work and things like that. (Care Home Staff 08)"

Furthermore, a number of participants raised questions and concerns about the training, supervision, and welfare of peer-mentors. Participants said it was important that the boundaries and scope of the role were considered and understood both by the people offering and receiving support.

"Clarity on boundaries... to protect (peer-mentors) because they could be used as an off-load... Is there some minimum training for them? At least having training around safeguarding, blurring of roles and expectations. (Family Member 01)"

"I think probably the only thing with the peer-mentoring (is) the ground rules and purpose. (Bereaved Family Member 06)"

The complexity of concerns and caveats expressed by participants provides support for the notion that supporting a person living in a care home, especially at times of deterioration and at the end-of-life, can be a potentially difficult and distressing time for family members. The findings presented suggest that peer-mentoring could be a potentially promising way to support families to prepare for and during these difficult times.

4. Discussion

4.1. Summary. The findings of this study suggest that although few had received peer-mentoring, these participants (current and bereaved family members and senior members of care home staff) suggested peer-mentoring would be beneficial for families of people living in care homes. Although some questioned whether families would feel comfortable talking about deterioration and the end-of-life with a peer-mentor, most agreed peer-mentors might normalise discussions about deterioration and provide families with an opportunity to acknowledge the possibility that the end-of-life could be approaching. Participants suggested that effective peer-mentors would need to have lived experience of supporting a relative in a care home, strong interpersonal and communication skills, and the ability to discuss deterioration and the end-of-life in a compassionate but factual manner. Furthermore, participants said that an effective peer-mentoring program should

create an atmosphere with an appropriate level of (in)formality to enable people to feel comfortable and at ease.

While the study team initially conceptualised peer-mentoring as a one-to-one, face-to-face activity, participants described various other formats that peer-mentoring could take. In addition, while the focus of the study was on whether peer-mentors could empower families to prepare for discussions and decisions about deterioration and the end-of-life, several participants suggested that developing a trusting relationship with a peer-mentor earlier in the care journey could facilitate open discussions. That the conversation was appropriately timed appeared to be important; however, it was widely acknowledged that the "right" time would be variable and dependent on the health of the person living in their care home and each family member's willingness to participate in discussion.

4.2. Comparison with Existing Research. Participants suggested peer-mentors could provide both "practical" and "emotional" support to families. This phrasing has also been highlighted in previous research [13] which explored public attitudes to talking about death and dying and therefore may shed light on the ways the public understand their support needs around preparing for discussions and decisions about deterioration and the end-of-life. Although existing research has suggested that peer-support can be beneficial for family members who support a person living at home [26, 31–33], the findings of the current study suggest that peer-mentors could also be beneficial to family members who support a relative living in a care home. Therefore, this finding supports previous literature which has highlighted the benefit of psychosocial support, particularly from other family members, both following admission to a care home and the end-of-life [48, 49].

Reviews of existing research have provided mixed results about whether the matching of mentors and mentees (by demographic characteristics or by situation) is an essential prerequisite to the development of successful mentoring relationships [25, 50]. Within the current study, a minority of participants who felt they were not a "typical carer," due to the perceived uniqueness of their situation, said they would prefer to have a peer-mentor who was similar to themselves. However, many participants noted that despite the uniqueness of each person's situation, there were often similarities across the experiences of people supporting a relative, and therefore, they would find benefit of working with a peer-mentor even if their background or situation was different to their own. Therefore, for the majority of participants, matching would not be essential.

Within this study, participants who already had access to support and expertise in their personal and professional networks stated that they may be less likely to engage with a peer-mentor. Research conducted in the USA by Perry et al.'s, which focussed on the impact of a peer-mentoring program on end-of-life planning for people receiving long-term dialysis, found that peer-mentoring was particularly beneficial for people from particular demographic groups [51]. In comparison to Caucasian participants, African

American participants who accessed peer-mentoring showed more prominent increases in the number of written advance care planning documents created and more prominent improvements in wellbeing, levels of anxiety, and individual confidence in talking about end-of-life wishes. The authors suggest that this could be due to peer-mentoring programs being less reliant on written information and more on a relationship-centred approach to support. Taken together, the findings of this study and of Perry et al. could provide a promising avenue for further research to explore ways to determine *who* may benefit most from a peer-mentoring program and *how* a program may be developed and implemented to meet the needs of people from particular social-economic and cultural backgrounds.

4.3. Strengths and Limitations. The strengths of the study include the inclusion of current and bereaved family and senior members of care home staff, multiple data coders during analysis, and extensive stakeholder engagement throughout. The use of opportunity sampling may have led to a selection bias which could raise questions about the representativeness of the people interviewed. However, the research team deliberately sought to increase diversity in the sample by advertising the study widely and including participants that could be underrepresented in the sample (for example, by contacting carer groups and care homes who support people from ethnically diverse backgrounds).

It is possible that the study may have been improved if participants were discussing their own lived experiences of a peer-mentoring program, rather than being asked for their thoughts on an abstract, imagined peer-mentoring program. However, the findings highlight some of the challenges of introducing the concept of peer-mentoring to people who have not received this type of support previously. The findings strongly suggest that this is a way of helping families prepare for deteriorations in their relative's health, so they are empowered to be involved in discussions and decisions advocating when their relative cannot.

4.4. Implications for Research and Practice. The findings of this study suggest that both families of care home residents and senior members of care home staff perceive a potential role for peer-mentors to support families of people who live in care homes. The findings also raise important issues that must be considered if a peer-mentoring program were to be developed and implemented, including ways that peer-mentors would be trained, supervised, and supported and ensuring both mentors and mentees understood the boundaries and scope of the support on offer. Furthermore, future research and development activities are needed to consider what format a peer-mentoring program should take and how to develop and evaluate a peer-mentoring program in practice.

5. Conclusions

Peer-mentoring could help empower families of people who live in care homes to prepare to be involved in discussions and decisions about deterioration and the end-of-life.

However, in order to do this, it is important for peer-mentors to have: lived experience of supporting a relative in a care home, strong interpersonal and communication skills, and the ability to discuss deterioration and the end-of-life in a compassionate but factual manner. Organisations that wish to develop an effective peer-mentoring program should consider how to create an atmosphere with an appropriate level of (in)formality and whether there could be a scope to introduce peer-mentors to mentees earlier in the care journey to enable a trusting relationship to develop that could facilitate open discussions about deterioration and the end-of-life.

Data Availability

The anonymised interview transcripts used to support the findings of this study are available from the corresponding author upon request.

Additional Points

What Is Known about This Topic. (i) Older people who live in care homes may have difficulties which limit their contributions to discussion and decisions about their care. (ii) Families often want to be involved in discussions and decisions about their relative's care but may not feel prepared to do so. (iii) Little is known about how to engage families of older care home residents in discussions and decisions about deterioration and end-of-life care. *What This Paper Adds.* (i) Participants said peer-mentoring would be beneficial for families of older people living in care homes. (ii) Families may prefer to seek a peer-mentor earlier in the care journey. (iii) Doing so could facilitate open discussions about deterioration and end-of-life care.

Disclosure

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this article.

Acknowledgments

Supplementary Materials

(i) Supplementary material 1: interview schedule for family members. (ii) Supplementary material 2: interview schedule for bereaved family members. (iii) Supplementary material 3: interview schedule for care home staff. (*Supplementary Materials*)

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