

Title

Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care homes

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Abstract

Background The older person with dementia has a limited life expectancy and the dying trajectory can be protracted and unpredictable. For good end-of-life care, early communication, exploration of residents' wishes, and identification of someone who can represent them, are important. In care homes the timing of these discussions, and who is involved is variable. Person-centred approaches to dementia care assume that people with dementia can actively participate in decisions about their lives. Less well understood is how this can inform end-of-life care decision making and complement information provided in advance care plans completed prior to, or at the point of admission to a care home.

Objectives To explore how older people with dementia discuss their priorities and preferences for end-of-life care.

Methods

An exploratory, qualitative study that used guided conversations with 18 people with dementia, living in six care homes. Participants were asked about their life in the care home, their health, thoughts for the future, and wishes surrounding end of life. Data were analysed thematically.

Results

People with dementia's accounts of life in the care home, what they valued, and the impact of having dementia on how they participated in decision making, provided key insights into care preferences. Three linked themes that had relevance for thinking and talking about end of life were identified: "dementia and decision making", "everyday relationships" and "place and purpose". Older people with dementia's accounts of everyday experiences of care, key relationships with family and care home staff members and whether they accepted the care home as their home demonstrated what was important for them now and for the future.

Conclusion

For older people living with a diagnosis of dementia, the experience of living and dying in a care home is inextricably linked. End-of-life care planning and decision making by health care professionals, care home staff and family could be enriched by exploring and documenting the preoccupations, key relationships and wishes about everyday care of people with dementia.

KEYWORDS – Advance Care Planning, Dementia, Dying, Long-term Care, Older People

What is already known about the topic?

- Entry to a care home does not mean that someone with dementia is in the end stage of the disease or dying. Although in the long term death is the expected outcome.
- The completion of advance care plans (ACPs) prior to entry to a care home and before there is significant impairment are recommended to ensure that the care older people receive are consistent with the goals.
- Little is known about how the everyday preferences of older people with dementia and the experience of living in a care home can inform decision making about end-of-life care.

What the paper adds:

- People with dementia can, when given the opportunity, articulate their preferences for care and views about living and dying in a care home.
- Preferences and priorities for end-of-life care are inextricably linked to the everyday experience of living in a care home and if it is viewed by the older person as their home.
- To complement Advance Care Plans completed prior to entry to the care home, it is vital that there is an ongoing exploration of how key relationships and views about everyday care can inform decision making about future care.

Introduction

There are an estimated 35.6 million people with dementia worldwide and this number is expected to nearly double every 20 years (World Health Organisation, 2012). Issues of mental capacity and the sensitivities of talking about dying mean that decisions on end-of-life care often rely on advance statements made prior to loss of capacity, proxy accounts from family, health care practitioners or care staff and retrospective analysis of patient records (Goodman et al., 2010). Less well understood is how people with dementia's current experience can inform planning and decision making around end-of-life care and complement information provided prior to, or at the point of, admission to a care home.

Background

In the developed world, the possibility of requiring a care home placement increases with advancing age and increasing numbers of the oldest old will live and die in long-term care/assisted living settings (Börsch-Supan et al., 2009). In the UK it is estimated that approximately a third of people with dementia live in long-term care facilities for adults (Comas-Herrera et al., 2007), including both nursing care homes (i.e. long-term care facilities with on-site nursing staff) and residential care homes (i.e. long-term care facilities that provide personal care only). Older people with dementia have a limited life expectancy (Rait et al., 2007). The majority of people do not enter a care home to die and it may not be their preferred place of care. Nevertheless, the assumption is that this will be the place where residents spend the last years and months of their lives. Longitudinal research with people with advanced dementia has described physical symptoms of ill health and key events that lead up to a person with dementia's death (Mitchell et al., 2009). However, accurate prognostication for older people with dementia is problematic and the evidence that supports

the use of advance care planning for residents in care homes is equivocal (Robinson et al., 2012, van der Steen, 2010).

The passage from living to active dying for older people with dementia in care homes can be protracted. This period of uncertainty affects how preferences and priorities are discussed, by whom and when, and whose opinions carry the most weight. There can be an imbalance between the individual's perspective, the system of care that is the care home and wider systems that provide end-of-life care (Froggatt et al., 2011). For example, residents may be striving to maintain their own identity other than one that defines them as near death or in need of particular types of care. Research that has discussed death and dying with older people in care homes, with and without dementia, suggests that advanced age and frailty does not mean residents would necessarily be more likely to want to talk about dying than the rest of the population (Mathie et al., 2012). These results raise issues about how residents' preferences for end-of-life care can be known and used to inform decision making about treatment, referral and place of care.

A review of the international literature of what is known about living with dementia from the older person's perspective (De Boer et al., 2007) has shown losses including the loss of memory, communication, orientation, control, autonomy, independence, self-esteem and relationships to be an important part of the older person with dementia's experience. When someone enters a care home they have already experienced multiple transitions between home and service providers. Moving into a care home can represent a profound experience of loss of independence, function, loved ones and a home (Hall et al., 2009, Mathie et al., 2012). Older people's current experience of care may be as important a factor in determining preferences and priorities for future care, as end of life wishes documented in the early stages of living with dementia.

This paper presents findings from interviews with older people who were living in a residential care home (i.e. providing personal care only) who either had a formal diagnosis of dementia, or were reported by staff to have the signs and symptoms consistent with a dementia diagnosis. It considers what the interviews revealed about people with dementia's ability to talk about end of life and living with dementia and how views on the everyday experience of living in a care home have the potential to inform advance care planning and the documentation of preferences and wishes for end-of-life care.

The aim of the study was to explore how older people with dementia discuss their priorities and preferences for end-of-life care, and how this might inform subsequent discussions with families and practitioners.

Method

This paper draws on findings from 18 interviews conducted as part of a four year longitudinal mixed method study entitled "Evidence Based Interventions for Dementia- End-of-Life" (EVIDEM-EOL). The interviews were exploratory, and part of Phase One of the study that tracked for one year, the care that 133 older people with dementia received across six residential care homes. Phase Two used the findings from Phase One to develop, in collaboration with care home staff and visiting health care professionals (General Practitioners (GPs), and community nurses), context specific end-of-life interventions for people with dementia. An account of the study methodology is provided elsewhere (Goodman et al., 2011). The interviews added the older persons' perspective to the data collected from the four-monthly note reviews and interviews with care home staff and health care professionals about end-of-life care.

The six care homes that agreed to participate were a mix of private and charitable ownerships, and were judged by the Care Quality Commission (i.e. the independent regulator of all health and social care services in England) and the primary care services they worked with to be providing good care.

A staged approach was used to support recruitment to the study. The study was explained to groups of residents and relatives at meetings in the care homes by the research team and older members of the public involvement in research (PIR) group. The PIR group is made up of members of the public, who with appropriate training and support, assist researchers with recruitment, undertake review of study documents and data analysis, and ensure that the research remains grounded in service user experience. Older people who were either formally diagnosed with dementia or were considered by the care home manager or care staff as having symptoms that were indicative of and consistent with a diagnosis of dementia, were approached and invited to take part in the study and also agree to be interviewed about living and dying in a care home.

Residents were not formally assessed as part of the research as to whether they had dementia as the study aimed to reflect the experience of older people with dementia based on how dementia had been defined by the care home staff and recorded in their care notes. Also, it became apparent that making a formal assessment of dementia a requirement for inclusion in the study could have implications for the older person's funding and how the care home organisation would have wanted to use this information. Care home staff in collaboration with the research team subsequently completed the Disability and Dementia scale on all the residents that participated and this provided a proxy measure of dementia (Gélinas et al., 1999).

Study participants were provided with photos of members of the research team and detailed information sheets. Single-sided laminated copies that summarized the key aims of the study

were left with residents as an aide-mémoire when talking about the study, and later when undertaking the interview. Those that expressed a willingness to participate then had the opportunity to discuss participation in more detail and formally consented to the interview (written or witnessed consent). The sample was purposive inasmuch as the aim was to recruit older people from each care home and include people that had different experiences of care (e.g. admitted from home or hospital) and been resident for different time periods. However, the ability to engage in a conversation was the overriding criteria for inclusion. The research team assumed the older person had the capacity to consent if they could understand what was required of them and the key aims of the study and had the ability to consent in the moment (Dewing, 2008). During the study, the focus was on enabling meaningful participation. Interviews were held in the person's room, or a place of their choosing where there were unlikely to be interruptions. Time was given to allowing the person to be relaxed in the company of the researcher. The interviews were undertaken by three members of the research team (NE, IM, ES). All were familiar with the care home routines and the care home staff. The interviews were semi-structured, conversational and flexible, so that the participant was able to focus on issues that were important to them. They took the form of a "guided conversation" (Gott et al., 2004). Specific prompts about end of life asked, "How would you like to be looked after when you are near the end of your life?" or, "How would you like to be looked after if you became ill/very poorly?" All interviews were recorded with the person's consent and were transcribed and anonymised.

Data were systematically sorted into categories that described the wide range of responses and initially kept as close as possible to the older persons' descriptions of events and experiences (Tesch, 1990). Categories were reviewed and where there was overlap or

similarities identified they were merged or linked together. As patterns, preoccupations, and differences were identified within and between categories, links were made, negative cases noted and key themes identified (Coffey and Atkinson, 1996). Themes were reviewed, and refined by two of the researchers and debated within the wider team research team and two members of the PIR group who had experience of family members living and dying in care homes.

Ethical Review

This study (REC reference: 08/H0502/74) received a favourable ethical opinion from the Southampton & South West Hampshire Research Ethics Committee (A) on 14 July 2008.

Results

Of the 133 people with dementia that participated 38 (29%) older people with dementia gave written consent to be interviewed, and one gave verbal witnessed consent. Eighteen older people participated in an interview with researchers, across the six care homes. Of the twenty who did not participate, one changed their mind and withdrew from the interview aspect of study. One interview was stopped because of the participant's distress, and others were either not available for interview because of care home activities, or because of their lack of capacity at the time of the interview, were no longer able to understand the study and consent in the moment. Thirteen of the interviewees were female and five were male (table 1). Eight had lived in the care home for eight months or less, ten had lived in the care home for over a year. The median length of stay was 13 months ranging from 3 to 61 months. The median age was 84.7 years ranging from 68.7 years to 92 years. Eleven older people had been admitted to the care home from their own home, five from the hospital and the remaining two from another care home and sheltered housing. All but four residents had a formal diagnosis of

dementia. Dementia related disability using the Disability Assessment for Dementia Scale (Gélinas et al., 1999) showed a wide spread of disability ranging from high levels of dysfunction (0%) to no disability (100%).

TABLE 1

The interviews with residents lasted between 20 and 60 min. The majority of residents were able to discuss their thoughts and feelings about living and dying in a care home but on their own terms, often choosing to focus on certain issues or stories, or how they had dealt with illness in the past. Some, partly because of difficulty in locating words to express themselves, gave short answers that were appropriate to the statements and questions but lacked detail. In two interviews, the older people knew that they were in a care home, made references to the routines of the care home, other residents, staff and visits from the GP and community nurse but also talked about their parents as if they were still alive or made comments that suggested they thought they were still in employment. Three themes that had relevance for thinking and talking about the end of life were identified; dementia and decision making, everyday relationships and the significance of purpose and place.

Dementia and decision making

Across the six care homes documented wishes and preferences such as advance care plans either predated entry to a care home, had been completed on admission or did not exist. The interviews showed that older people were aware that they had memory loss and dementia and this initially affected how they participated in the interviews. They would remind the interviewers that their memory was bad or that they might not have anything interesting to say. Several apologised throughout the interviews that they forgot things and were confused about time and place. This person was very clear how he was affected by dementia:

They told me, and this is only what I've been told 'cos I don't know, I had apparently a minor stroke and I think it affected the, is it the vascular?....I don't

remember all these things 'cos you don't, and it gave me a total short memory loss and that was it basically. [Thomas]

Knowing that they had dementia affected confidence in expressing opinions, self-esteem and whether they thought their views were worth listening to and if expressed that they would be noted or trusted. Derogatory terms were used, one called herself a "mouldy oldie", another "going potty" to describe her situation:

Yes oh and I've got my...What's it called? See I think you may have picked the wrong person cos I'm going potty, I can't remember everything...I don't like it being like this, but there's nothing I can [do] about it really, I don't think.

[Patricia]

Later in the interview, even though she could not remember the words for hospital or resuscitation, and had suggested she was not worth listening to, she was able to articulate that if she became ill she would not want to go to hospital, she would want to die in the care home:

No I think if something goes wrong and I'm horrible or anything, I would rather be dead and not be in...what is it? Sort of walking around not knowing what I'm doing...Yeah I would rather be dead here than anywhere else and I know it's gonna happen sometime. [Patricia]

Having dementia combined with living in a care home meant the older people often accepted that staff, family members and visiting clinicians would make decisions on their behalf. This man assumed that because of his age, others would make the decision not to treat any future illnesses:

And people of my age, they don't [admit to hospital]... they just let us kick the bucket, don't they? Do you know what I mean by 'kick the bucket'? [James]

Interestingly, the next, unprompted, statement he made was that he wouldn't mind seeing a priest. This would suggest that initiating the conversation about future care and dying had provided an opportunity to make a request that otherwise might not have been made.

This woman understood why having dementia meant there were restrictions on going out alone, unlike the preceding comment, she did not think decision making on her behalf was reasonable:

Well I'm not allowed to [go out alone] in case I forget where I am and I don't know my way back, but, I said "can I just go and have a walk around the grounds", "no". I'd obviously find my way back from out in the grounds wouldn't I, I would have thought. I said that this afternoon to one of the girls "can I go and have a walk round" she said "oh no" [Elizabeth]

Despite the noted hesitancy, older people's ability to express preferences was a consistent finding in the majority of the interviews, although not all were able, or wanted to be specific about future care. The interviews demonstrated awareness of their disease and the associated limitations that the older people lived with as residents in care homes. Given the opportunity, people with dementia engaged in conversations about preferences for future care as well as how they lived day to day. Linked to this was how the older people described their everyday experiences of care and the opportunities there were to develop conversations and relationships.

The everyday relationships

It is well documented that the quality of relationships between care home staff and residents informs older people's sense of wellbeing and quality of life. This was reflected in how priorities and preferences for future care were expressed or alluded to in the interviews. Older people's views were shaped by how they were cared for on a day-to-day basis and whether the older person believed there were people who understood them. Their comments on how they were looked after had the potential to inform statements about preferred place of death and what they valued (or disliked) about the care they could receive in the future. For example, one woman whose conversation ranged over many, often seemingly unconnected issues, kept coming back to her dislike of being disturbed and the noise of other residents and what she saw as staff manhandling her. This account provided an insight of how she wanted to be talked to, that could have been recorded and informed current and future care. She wanted to be able to rest undisturbed:

...like I'm being woken out of my rest in other words, and all it pulled...turn this way and turn that way and they are turning me different ways, you see, I don't wake in my own time, I wake in, I'm woken up in other words...but I can't stand them saying "turn over to"... "will you turn this way?" and "will you turn that way?" and "will you turn back the other way?" and it's all that you are not left to rest you see. [Doris]

The quality of the relationships that people anticipated they would experience was a recurrent theme. One resident expressed it as friendliness and responsiveness, she was confident the staff would look after her and would involve the GP when needed. She had returned to the care home from the hospital and knew that she did not want to leave again:

It's the friendliness that keeps you going, I mean if you are not well, they're in there in a shot...they *really* (resident emphasis) look after me, they'll call the doctor, well I've had two good years this time, I've been in a while, but I've, the last two years I've got really well " [Alice]

Similarly, other residents identified that living in a care home was a positive experience with one man [James] repeating that it was "paradise" throughout the interview, and another saying:

I like it here. It's very good. I live here now. This is my home now. [Irene].

For them the care home had become the place where they felt supported and where they would want to stay. Their accounts of the everyday experience reinforced that the care home was the preferred place of care. However, for many, distinctions were still made between the kindness of the staff and the more negative experiences of a regimented approach to care, the loss of their homes and the limited opportunities to feel that they were doing something meaningful. These older people lived with the knowledge this was their home but it was a compromise. There was an expressed ambivalence about living in the care home; a finding irrespective of which care home they lived in.

If the older person did not feel they had a good relationship with members of staff then the negative impact of living in a care home was more keenly felt. One resident thought the care workers were nice but more like "schoolgirls" and at the end of the interview commented it had been a relief to talk to someone. Some talked in more detail of the difficulties of forming relationships:

Well, you go in and you talk to them but it's not like you would to an ordinary friend, you know, they're a little bit, "keep to myself" sort of thing. [Edith].

When asked to whom they spoke if they had a problem, one resident said:

one of the staff I suppose...does that sound right? [Mary].

For older people living at home, often it is family that are identified as the people in whom they would confide. In these interviews family members were important, and two people identified their daughters as the people they would want to talk to, however, it could not be assumed that they would know what the older person thought or wanted. One resident spoke of not wanting to upset her daughter by talking about dying and in this example the woman was aware that her funeral could lead to family dissension and so had made sure the arrangements were in place and paid for:

I can't remember the name of the funeral people and my youngest son he's got the details, he's got all the papers, I don't want them (children) fighting saying ooh we have to pay for this. I wanted to do it myself. ” [Alice]

This resident was also very specific about whom she would discuss a problem with and that it was not a family member, saying:

...she's [care worker] the one that would be there for me you see. [Alice].

This response was unique, even though the majority of residents recognised that the staff members were kind and caring. The interviews revealed a wide variation in the quality of relationships with care staff and family members that in turn affected their confidence that their wishes would be known. It was not clear from the residents' care notes if care home staff knew who were the significant confidante, family member and/or member of staff for the older person.

That not all the participants felt they had a particular relationship with the care home staff was starkly illustrated by this resident's observation:

Well I like the staff, everything is very pleasant

Interviewer: Is there anyone in particular?

No, I'm shared out amongst everybody I think [Margaret]

An inclination for hospital care at the end of life could be based on an expectation that they would receive better care, or that there would be people who would pay attention to their needs and feelings:

I feel I'd be looked after [in hospital] by very interesting people and people who especially take an interest in your feelings. [Kathleen]

Significance of purpose and place

Conversation was often framed in relation to what they had already lost, whether this was their home or family, and most importantly how these losses had an impact on whether they now had a purpose in life. Dementia compounded that experience but it was multi-layered.

For this person the loss of function was linked to a loss of purpose:

Well my legs are going, I can't walk, I can hardly walk I mean, I can't say I can't walk cos I can and I do, but it's pretty useless you know they don't go far for a start, and even if we did I don't know how to finish that ... It's not much good, I get the feeling it's not much good being here at all, I'm getting nothing done. I can't help anybody else in here, what's the point of it all, I like to be useful. I can't do anything [John]

The older people had lived longer than family and friends; they knew that further changes could occur. Some made reference to the possibility of a further move to hospital or nursing

home if they became more dependent. Some were hopeful that they could return home or to their family. Their preferred place of care was somewhere that was not necessarily attainable:

I just wish I was going home...and I don't say to her [daughter] "can I come and live with you" because I don't think, I can't be going because I've only seen her husband about twice because he's a new one of course... [Eileen].

This woman explained her repeated walking up and down the corridors of the care home as a way of keeping fit. She hoped that the frequent exercise would make her strong enough to leave and go and live with her daughter. Whilst her hope of being able to leave was probably unrealistic it provided an explanation for what staff had interpreted as purposeless walking secondary to her dementia. Not being reconciled to being in a care home affected how older people talked about the future and their preferred place of care:

No future I wonder what future I've got, if this think (dementia) in my head works I hope it doesn't, don't go a bit do lally , oh dear I don't know there's nothing I really more to say, it's nice here and they do work hard but I don't want to stay here anymore.[Elizabeth]

Three older people appeared depressed and talked, unprompted, of wanting their lives to end. Two said they had not discussed their feeling with anyone else. For all these people permission was asked for and given to inform a member of staff or GP about how they felt and the researcher followed up with staff after the interview.

Even when residents were reconciled to living in a care home and appreciative of the support that they received from staff, it was often their sadness and losses that they returned to again and again. Thinking about their own care needs and preferred place of care was

overshadowed by these past experiences. Where they died was inconsequential when set against their sadness at no longer being in a place with those they loved:

I'm quite happy here if you can be happy by yourself and you've just lost your wife and your children aren't that near to you. When (wife) died she was wonderful, she was lovely, oh she was she was, I sit there very often in the afternoon and I have a damned good cry, I do honestly, but I just can't help it. I feel she's here and I want to talk to her and words won't come, so tears come instead. [William]

Talking about the past could have been a reflection of the person's cognitive state. It could also show what was important in that person's everyday life; the source of their sadness (bereavement, losing independence and home, losing function and purpose) and what improved that experience, and made living and dying in a care home a desirable option (confidence in the carers, having people who knew your story, likes and dislikes).

The findings demonstrate the complexity of loss, the heterogeneity of experience and how circumstantial evidence such as care preferences, repeated narratives and behaviour (e.g. crying) can provide otherwise unknown information about how someone with dementia might want to be (or not) cared for at the end of life.

Discussion

The older people in this study were experiencing cognitive decline and relied on others for their day-to-day care. For many an awareness of their dementia affected their confidence about whether their views were worth listening to, and if they could influence decision making about current and future care. Once given the opportunity however, their accounts of everyday experiences of care, key relationships, and whether they accepted the care home as

their home, demonstrated what was important to them now, and for the future. Their conversations were wide ranging, characterised by uncertainty about their future and sometimes disconnected. They nevertheless provided examples of good and bad experiences that could ensure the person with dementia's voice is included in discussions and documentation of future wishes and care preferences.

Research with frail older people that do not have dementia but are in the last years of life has found that for the older person, living and dying are inextricably linked and that dying is seldom seen or experienced as a discrete process to be planned for or discussed (Gott et al., 2004, Nicholson et al., 2012). These themes were also evident in interviews with older people in this study who in addition, were dependent on others and experiencing cognitive decline. Results suggest that approaches that support advance care planning need to create over time, opportunities to capture how living with dementia, the significance of particular relationships and what living (and dying) in a care home means to the individual. The creation of 'communicative space' (Kemmis, 2001) has been proposed by Froggatt et al as one way to bridge the life world of the individuals and the wider system structures and approaches that exist for their care (Froggatt et al., 2011). Creating communicative space is a conscious process that balances service and system priorities for end-of-life care to (rightly) reduce unnecessary interventions, promote comfort and increase clarity in decision making, with the older person's perspective about *how* care should be provided and by whom.

Exley and Allen (Exley and Allen, 2007), in a critique of "home" as the preferred place for end-of-life care, observe that "home" is not merely about a physical space but the social and emotional relationships that are experienced there. The need for meaningful relationships, purpose, and feeling safe for people with dementia in long-term care settings at the end of life are known (Birch and Draper, 2008, Hall et al., 2009, Reitingger et al., 2003, Ryan et al., 2009, Small, 2007). The few residents that could identify relationships that made them feel

they were at “home”, supported that view, many, however, alluded to its absence. The interviews in this study were often halting, repetitive and needed interpretation. Nevertheless the persistent need for what others have called “relational dignity” (Pleschberger, 2007) was evident in their accounts.

Research that defines the dying experience for people with dementia persists in being defined by health care professionals and family members (Lawrence et al., 2011). People with dementia can discuss living and dying with the disease and their preoccupations extend beyond physical care needs, and decision making about preferred place of care (Moriarty et al., 2012). The challenge is how to develop practice and processes that reflect that fact.

In long-term care settings, the documentation of resident priorities can be a routine part of the admission processes; it may not inform decisions made months or years later. The priority therefore, is to develop and test complex interventions that ensure the meaningful participation of the person with dementia in ongoing discussions and decision making about their future care.

Limitations

The number of older people with dementia interviewed was small and the interviews were exploratory. Whilst there were recurring themes, data saturation may not have been achieved. Those who participated may have been unusual in being able to participate in a conversational interview. The residents interviewed were able to maintain a conversation and be orientated to the topic and the questions asked, even if they could not later recall the interview. However, some interviews were short or wide ranging in their content and focus and this made interpretation difficult. The researchers did not have a day to day/on-going relationship with the residents, or know the older person’s story. There could have been messages and meaning in the data that was missed because we were unable to understand

what was meant. It is a limitation of the study that alternative methods of communicating ideas and views about end of life were not explored through observation, visual aids or biography and stories. Careful attention was nevertheless paid to what older people thought was important about living and dying, and how their accounts of the deaths of friends and relatives reinforced statements made regarding how they thought about their own mortality.

Conclusion

The systematic introduction of advance care planning (ACP) for people with dementia can reduce the incidence of inappropriate life prolonging treatments, involve family members in decision making and improve overall delivery of end-of-life care (Detering et al., 2010).

There is limited evidence for the effectiveness of ACP by the time a person is in receipt of long-term care, leading some to conclude that it may be too late for people with dementia and that the process should be started earlier (Robinson et al., 2012). However, for this population, the single act of agreeing an advance care plan prior to, or at the point of care home admission may have the unintended consequence of excluding the person with dementia, from ongoing discussions and decisions about their future care.

Implications for Policy, Practice and Research

End-of-life policy and practice recommend the use of end-of-life care tools and frameworks to support older people dying in long-term care settings (Department of Health 2008). The findings presented here suggest that methods of assessment, care planning and documentation that focus on dying could be enriched by more careful attention to, and documentation of, the everyday accounts and observations of what older people with dementia in long-term care identify as important. Further research is needed that tests the impact of incorporating people

with dementia's preferences over time, on end-of-life care decision making and related outcomes such as place of death.

Acknowledgements

We would like to thank the care homes, the people with dementia who participated in interviews and consented to taking part in the study, carers, and NHS staff who participated in this study. We would also like to thank North Thames Dementia and Neurodegenerative Disease Network (DeNDRoN) for supplying the additional funding required to complete recruitment. Finally, we would like to thank the members of the Public Involvement in Research group for their help with recruitment and data analysis and members of the Steering group for their assistance in developing the study.

Disclaimer

This report presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1005). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

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Table

Table 1 Characteristics of the sample

Pseudonym	Gender	Age at time of interview (Mdn=84.7)	Length of stay in months (Mdn=13)	Admitted from	Formal diagnosis of dementia
Patricia	Female	68.7	17	Own home	Yes
Margaret	Female	89.1	25	Own home	Yes
Mary	Female	83.2	48	Own home	Yes
Joan	Female	85	14	Own home	Yes
John	Male	87.7	5	Other care home	Yes
Joyce	Female	81.5	61	Sheltered/Warden controlled housing	Yes
Dorothy	Female	90.4	8	Own home	No
William	Male	87.9	4	Own home	Yes
George	Male	89.5	22	Own home	Yes
Kathleen	Female	83.9	4	Own home	Yes
Doris	Female	88.2	13	Own home	Yes
Irene	Female	82	3	Hospital	Yes
James	Male	92	15	Own home	No
Thomas	Male	76.6	13	Hospital	Yes
Elizabeth	Female	74.1	16	Hospital	No
Eileen	Female	85.1	5	Hospital	Yes
Alice	Female	84.3	4	Own home	No
Edith	Female	83.2	3	Hospital	Yes