

Northumbria Research Link

Citation: Poole, Marie, Bamford, Claire, McLellan, Emma, Lee, Richard, Exley, Catherine, Hughes, Julian, Harrison-Dening, Karen and Robinson, Louise (2018) End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative Medicine*, 32 (3). pp. 631-642. ISSN 0269-2163

Published by: SAGE

URL: <https://doi.org/10.1177/0269216317736033>
<<https://doi.org/10.1177/0269216317736033>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/36540/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)

Poole, M., McLellan, E., Bamford, C., Lee, R.P., Exley, C., Hughes, J.C., Harrison-Dening, K., Robinson, L. (2018). End of life care: A qualitative study comparing the views of people with dementia and family carers.

Abstract

Background: In recent years UK policy has increasingly recognised the importance of end of life care in dementia. Whilst professional consensus on optimal palliative care in dementia has been reported, little is known about the perspectives of people with dementia and family carers.

Aim: To compare the views of people with dementia and family carers of people with dementia (current and recently bereaved) on optimal end of life care in dementia.

Design: Semi-structured qualitative interviews (21) and a focus group were conducted. Data were thematically analysed.

Setting/participants: Participants comprised people with early stage dementia, living at home in the North-East of England (n=11); and current and bereaved carers (n=25) from six services providing end of life care in England.

Findings: Seven areas were identified as important to end of life care for people with dementia and/or family carers. People with dementia and carers expressed the need for: receiving care in place; ensuring comfort; and a skilled care team. However they disagreed about the importance of planning for the future; and the role of families in organising care and future decision making.

Conclusions: Further comparison of our findings with expert consensus views highlighted key areas of divergence and agreement. Discordant views concerning perceptions of dementia as a palliative condition, responsibility for future decision-making and the practical co-ordination of end of life care may undermine the provision of optimal palliative care. Professionals must explore and recognise the individual perspectives of people with dementia and family carers.

Keywords

Terminal care, dementia, palliative care, people with dementia, family caregivers, qualitative research

Key Statements

What is already known about this topic?

- End of life care for people with dementia is often inadequate and requires improvement.

- The views, wishes and preferences of people with dementia are poorly understood and family carer perspectives are under-researched.

What this paper adds

- People with dementia and family carers do not always share views on what is key to achieving good end of life care.
- The views of people with dementia and family carers do not always accord with professional consensus on optimal end of life care.

Implications for practice, theory or policy

- Practitioners need to find ways of improving understanding of dementia as a palliative condition. This will enhance the relevance of advance care planning for people with dementia and family carers.
- Practitioners should explore assumptions about decision-making towards the end of life to highlight and address any tensions between people with dementia and family carers, to increase carer confidence in decision-making and avoid additional burden and anxiety.

Introduction

Our rapidly ageing populations are leading to more people, globally, living with age-related illnesses like dementia, causing considerable concern for future health and social care provision ¹. Policy on dementia care has tended to focus on ensuring people maintain quality of life and 'live well' with the illness through earlier diagnosis and intervention. The importance of improving care towards and at end of life for older people in general ², and especially those with dementia, is increasingly recognised ³⁻⁶. Research evaluating the organisation and provision of end of life care for people with dementia and their families gives cause for concern in terms of the quality and nature of such care⁷⁻¹⁰.

In principle, good end of life care is supported by individualised care planning which reflects the needs and wishes of the dying person and those important to them. However people with dementia may not view future care planning as a priority ¹¹, and may be excluded from decision making and experience limited agency in securing good end of life care ¹². Currently very few people with dementia die at home or with hospice care, with the majority dying in care homes and in acute hospitals ¹³. This suggests that many people with dementia do not die in their preferred place of care, and highlights the need

to increase agency and act on, as well as elicit, preferences for end of life care ¹².

Increasing cognitive impairment and decreased ability to communicate as dementia becomes more severe, means it is important to ascertain a person's views about their future care in the earlier stages of the illness ¹⁴. In practice, this rarely occurs, since health professionals struggle to find the 'right time' to initiate such discussions ¹⁵. Discussing future care is further complicated by the fact that people with early stage dementia often prefer to concentrate on living in the present rather than planning ahead ¹¹. When discussions are delayed until the more advanced phase, professionals may place greater emphasis on physical and clinical issues, rather than individual values and preferences ¹⁶.

A Delphi consensus of 64 expert professionals (health professionals and researchers) specialising in palliative and/or dementia care from 23 countries, identified essential domains for good quality palliative care in dementia ⁵ (Figure 1). Subsequent research confirmed the importance of optimal treatment of symptoms and providing of comfort; family involvement; and optimal communication and shared decision-making; to practitioners ¹⁷.

Figure 1: Domains for optimal palliative care for people with dementia ⁵.

[Insert figure 1 here please]

Little research to date has explored the views of people with dementia on end of life care ¹⁸⁻²⁰. There is also a limited understanding of family carer perspectives ^{8, 21, 22}, with their views often sought retrospectively in the post-bereavement period ²³. The 2016 World Alzheimer's Report recommended the urgent need to explore the perspectives of people with dementia to better inform care management and service delivery ²⁴. The aim of this study was to investigate the views of people with dementia and the views of family carers of people with dementia (both current and recently bereaved carers) on factors important to them regarding care towards and at end of life.

Methods

A qualitative approach was adopted to explore the views of people with dementia and family carers about end of life care. This was underpinned by a social constructivist epistemological stance ²⁵. The reporting of our research is consistent with relevant guidance on reporting qualitative research ²⁶.

All data were collected between January and December 2015. Figure 2 summarises the process of recruitment. *[Insert figure 2 here please]*

People with earlier stages of dementia (diagnosis in the past three years and/or, where available, a Mini Mental State Examination score of > 20) were recruited via the local clinical research network and a national voluntary registry to participate using Q-sort methodology to seek their views on factors important to them in end of life care. The full methods and findings of this are published elsewhere ²⁷. However to explore responses in-depth and better understand their views on a broader range of aspects of end of life care, additional face-to-face, qualitative interviews were conducted by MP immediately after completion of the Q-sort. Written consent was obtained from all participants.

The interviews and focus group with carers explored experience of services, care needs and components of good end of life care. Separate interview schedules were developed for current and bereaved carers. All participants were given the option to be interviewed either in their own home, at the care service, or at the university. The interviews with people with dementia and current carers explored mainly hypothetical views about end of life care, while those with bereaved carers considered personal experiences of palliative care. Interviews were conducted by CB, RPL, EM and MP.

Data were audio recorded, transcribed and anonymised before analysis. Each participant was assigned a unique numeric identifier; used to identify quotations. For current and bereaved carers, the type of service from which they were recruited is also indicated.

A thematic approach to analysis was adopted ²⁸. Initially, individual researchers (EM, MP) read and re-read a selection of transcripts to become familiar with the data. The researchers noted areas of interest and potential themes independently, compared ideas and discussed these in workshops (CB, CE, RPL, EM, MP, LR). Following discussion of emergent themes, we applied the thematic framework to further transcripts and discussed collectively in a subsequent data workshop. Once the framework was agreed, this was applied to all transcripts. This inductive process enabled identification of the most salient points from the data. EM and MP wrote narrative summaries to explore emergent themes in more detail by considering the summaries alongside existing theory and literature. This enabled us to compare how these complemented existing ideas or were unique to our research. Data saturation was reached during analysis when no new themes emerged from the data.

Findings

Eleven people with dementia and 25 family carers participated in the study (see Figure 3). People with dementia and family carers were not family dyads.

[Insert figure 3 here please]

Our findings highlight seven aspects core to the provision of good quality care towards, and at the end of life (see Table 1). Views and preferences varied both within and between people with dementia and family carers. In general, both groups emphasised the importance of remaining in their preferred place of care, and ensuring comfort and minimising distress. In contrast, people with dementia and family carers disagreed on the importance of future care planning; who was responsible for decision-making, the co-ordination of end of life care and the core competencies and skills needed by care providers to deliver good end of life care.

Being cared for 'in place'

Most participants with dementia wished to stay at home for as long as possible. Some conceded that their declining health might require full time institutional care; however, others did not consider this inevitable and hoped to remain in their own home for end of life care with appropriate support.

I would like to have my end of life care at home, all of it if possible [...] I think I'd like to stay at home if possible, I think my wife would like me to stay at home as well if I can. (Person with dementia, 8)

Regardless of whether the person with dementia lived at home or in a care home, all carers preferred their relative to remain in place rather than be admitted to hospital for end of life care. Hospitalisation was perceived to cause distress and upheaval for the person with dementia due to the unfamiliar environment and people. To facilitate continuity of care, many carers welcomed the opportunity to make appropriate plans to prevent unnecessary hospital admission.

I sort of agreed with everybody here and the GP that if at all possible there would be no hospitalisation again 'cause I personally felt she got far better care here, than she would get in hospital. I mean I'm not criticising the hospital, I just think places like this are better set up for caring than a hospital ward is and it seemed to me she was far less disturbed by being here with the people around her that, she kind of recognised... (Bereaved carer 1, Supported living service 2)

When hospital admission was unavoidable, carers often emphasised the importance of the person with dementia returning to their usual place of

care as soon as possible. This could be facilitated by communication between families, care home staff and hospital practitioners.

I said “my mother’s 97, she can’t recover, she’s had a fantastic life full of love, she loved her children, she loved her family, I said and she’s going back to where she belongs” [...] my mother isn’t going to live longer than three days, you’ve told me that, so she’s not going in the ward” – so then they had consultation and they rang (care home) and the home backed me, they said, “This is her home, she’s coming home, to die” (Bereaved carer 3, Supported living service 2)

Being comfortable at the end of life

Our findings indicate that people with dementia and carers considered being comfortable and pain-free as essential to good end of life care. They saw this as a basic requirement, readily achievable by carers attending to the “little things”.

The key things for Mum is just for her to be kept clean, comfortable, pain free, and not distressed. And you know, I think that’s quite easily achieved. (Current carer 1, Specialist EMI service 2)

... I think the pain relief, pain management, one of the most important things when you’re getting towards the end. In my

own opinion, I'd rather have the pain decrease, even if it meant that I was going to live shorter. (Person with dementia, 8)

Although generally there were assumptions that ensuring comfort should be a standard competency in generalist staff providing end of life care, one carer recognised the role of specialist services in achieving this.

I wouldn't like him to suffer that's one thing I wouldn't like, that's where the palliative nurses come in isn't it (Current carer 4, Residential/nursing home 1)

In addition to physical comfort, both people with dementia and carers also took a holistic view of comfort and agreed on the importance of psychosocial elements such as emotional comfort, compassion and spirituality.

There's more to it than just being a medical aspect being considered. Its welfare and compassion and all the factors like that. (Person with dementia, 3)

Whereas people with dementia often considered care staff to be responsible for practical aspects of comfort and care, family were commonly viewed as the main source of emotional support. The desire for family to be with them at the end of life was frequently expressed. Although family carers wished to be present at the end of life, they also valued the important role that care staff could play in providing emotional support to people with dementia.

Bereaved carers drew comfort from knowing that staff attended to psychosocial as well as physical needs.

I think to me as long as I've got [husband], as long as we're together that's all that matters to me. (Person with dementia, 5)

she [staff carer] spent two or three hours every night reading the bible to my mother [...] they were looking after her, they kept making sure she was comfortable, they kept moistening her face... and going in all the time and talking to her. (Bereaved carer 3, Supported living service 2)

A skilled care team

People with dementia and carers agreed that the delivery of good quality end of life required well-trained staff, however they recognised the difficulties of achieving this in the context of limited resources and challenging conditions.

...the salary that the carers get isn't enough, for the work they do, they're on minimum wage I think...and they're long hours... you're on the go all the time, I wouldn't like their job (bereaved carer 2, Supported living service 2)

Being skilled in basic elements of care such as feeding and medication was seen as essential. People with dementia, in particular, assumed that staff would be sufficiently skilled to deliver these fundamental aspects of end of life care.

I would expect that to happen [recognising pain and distress] as a matter of course. (Person with dementia, 7)

In addition, people with dementia and carers considered it necessary for staff to be trained and skilled in the delivery of individualised and person-centred care. Whilst people with dementia often expected staff to be able to instinctively provide such care to all, family carers recognised the need to develop relationships in order to be able to provide individualised care.

Compassion is automatic surely (Person with dementia, 1)

They liked him they loved him even, they were fond of him and they cared for him as somebody they were fond of. They responded to his needs... (Bereaved carer 3, Supported living service 1)

People with dementia and carers also recognised that staff providing end of life dementia care should have additional or specialist training to ensure a good standard of care. Such specialism was considered necessary to meet needs particular to dementia at end of life.

So I think it's imperative that the training standards for people who work with Alzheimer's have extra input. (Person with dementia, 11)

Making future plans: importance and value

Discussing and planning future care was one area where considerable tensions existed between the views of people with dementia and family carers. However current and bereaved carers also tended to have differing views on the value of planning ahead. People with dementia commonly reported they had already made adequate arrangements for their end of life care, often alluding to having their 'affairs in order'. However further investigation revealed that people tended to focus on practical post-death arrangements such as wills, finance and funeral arrangements rather than specifics of their daily care towards end of life.

Yeah, well everything is all sorted so it's everything is done, so if I pass away then everything is sorted. (Person with dementia, 10)

Her only wishes were we weren't to make any fuss and that she was to be cremated not buried, [...] obviously she was insistent that she made a will, [...] she was a very practical lady really. So, she saw to the practical things [...] but, no I can't say we did

*really talk about end of life care, no. (Bereaved carer 1,
Supported living service 2)*

Such plans were often regarded as complete, with no need to revisit or amend them in the future. Furthermore people with dementia were often unaware of other plans, especially related to their health and future care, which they could put in place. One notable exception was a person with dementia who had previously worked in dementia care (person with dementia, 12) and was fully aware of the need to include these areas in their detailed care plan.

*We've got a will made out, for me and [Wife] like, but I don't
know what, what we could do other than that like. (Person with
dementia, 3)*

*So I was thinking, well I've done all this, but I hadn't in a sense.
The care plan, all I did for the care plan part- I did my end of life,
but the care part is like my medication, injections, and how I like
to drink water. (Person with dementia, 12)*

As future plans primarily related to financial and funeral arrangements, some participants did not see the value of sharing this 'private' information with care providers. Instead, these plans were informally discussed with trusted family members, were frequently undocumented and ran the risk of not being legally recognised. Furthermore, misunderstanding around end of

life care planning meant responsibility for planning was often considered personal. For those individuals, the involvement of care providers was not considered legitimate, and potentially intrusive.

IV- Well, I'll have a plan myself...But it might not involve any medical people or care people.

I Right, so it might not be a formal, written down one.

IV- Formal - no but I'll have a good idea what I want to do.

I ...And how will you let others know?

IV- I'll discuss it with my wife. (Person with dementia, 8)

I: And, how would you feel if staff at [service] asked you about, wishes about end of life and things like that?

IV: Well they cannot it's not their job.

I: You don't see that as their job, to be planning ahead?

IV: It's what I said ... I don't think it's got anything to do with them, because I mean it's something between you, the family...(Current carer 2, Residential/nursing home 1)

In addition, neither group seemed to understand dementia as a palliative condition. This included bereaved carers who attributed death to a general physical and mental decline, usually related to other co-morbidities, rather than recognising dementia as a terminal illness.

... the GP had been and the carers told me that, you know, this was looking like the beginning of the end and then he steadied a bit, he didn't get better, but he levelled out a bit, so that prolonged things [...] Just a general deterioration. (Bereaved carer 3, Supported living service 1)

This impacted on the perceived value of making future plans and the preparedness of people with dementia and families to have timely discussions concerning prognostication and planning. Predictions about death were not influenced by the diagnosis of dementia, therefore a dementia diagnosis may not drive the need for planning end of life care in the same way as other conditions which are commonly understood as terminal, for example cancer.

Well you can't plan - for something in place when you don't know when you're going to die. (Person with dementia, 3)

In addition, some people with dementia preferred to focus on their current situation and capabilities and not on future decisions which they found upsetting. Some carers also found looking towards the future challenging. In the quotes below, participants distance themselves from end of life, hinting at the desire to consider end of life as a future matter.

... I can't relate to it [EoL]. [...], I'm fit and well. (Person with dementia, 12)

It's [EoLC], quite a difficult subject to talk about, isn't it? [...] I suppose, the nearer you get to being in that situation more questions you, you could think of (Current carer 1, Residential/nursing home 1)

Although family carers similarly struggled to see the value of planning for the future in the abstract, they often responded positively to specific aspects of health care planning such as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). This suggests it may be easier for people to establish what they do not want when faced with clearly defined choices rather than trying to plan for a multitude of unknown potential eventualities. Carers often expressed strong feelings about resuscitation, fearing that this could have damaging short and long-term consequences for the person with dementia.

Obviously, if it's a chest infection, whatever, antibiotics, but other than that, you know, it's do not resuscitate. She's 92. She has, really, no quality of life. We don't want to lose her, but we don't want her to live in any worse situation than she's in. (Current carer 1, Specialist EMI service 2)

Faith in family members

In relation to the previous section on planning, our findings indicate that sharing wishes and preferences for end of life, does not routinely happen in

many families. In addition, people with dementia and family carers may place different value on the importance of sharing vital information to inform decisions at end of life. People with dementia may encounter a long phase in which their ability to express their wishes and preferences is compromised, in comparison with other palliative conditions. Therefore dependency on others to fulfil their wishes may be particularly strong.

People with dementia often assumed that their families would already know their values and wishes and automatically fulfil an advocacy role for them if they became unable to communicate their preferences. This presumed knowledge was based on long standing familial relationships, in which people with dementia often described putting their trust and faith in family. Such trust was often not formalised by people with dementia, although a small number had established Lasting Power of Attorney (LPA), thus legally devolving responsibilities to others.

I would have faith in what they [family] are doing. It's as simple as that. I know my family very well, yeah. (Person with dementia, 7)

I've done the things that I should do. You know, I've made a will and I've done the power of attorney, or it's well on the way. (Person with dementia, 12)

Despite expressions of confidence from people with dementia that families would uphold their wishes, carers often felt that they hadn't explicitly discussed wishes and preferences with their relative. Thus carers frequently felt inadequately equipped to advocate care preferences, even in close and long established relationships. This was a source of distress to families who felt under pressure to make the right choices and generated concern around the amount of 'guess-work' families may be faced with when trying to make decisions on their relative's behalf.

I mean I've known him since I was 18...and I'm 78 now. [...] we never ever talked about dying...now I wish we had done...it's a funny thing you know, it is because if me and (husband) had discussed it I would say "right I'm doing his wishes" but now I don't know... (Current carer 4, Residential/nursing home 1)

Although some carers appreciated the value of documenting the person with dementia's wishes and preferences to ensure they made the right choices on their relative's behalf and also to provide them with peace of mind, several carers felt that they had missed the chance to have such discussions and expressed regret at this lost opportunity.

But like I say, we didn't ever have that discussion, 'cause we didn't think it [dementia] would happen to her, and by the time

*things started to happen, it was too late. (Bereaved carer 1,
Specialist EMI service 2)*

Trust in professionals

Many of the people with dementia and family carers in this study believed practitioners to be eminently capable of, and better equipped for making decisions concerning end of life care than themselves. They often felt that healthcare professionals would have a better understanding of the needs of the person with dementia, and therefore would be able to make important decisions concerning treatment and care at end of life. Thus the confidence that people with dementia had in their families to make decisions on their behalf also extended to healthcare practitioners, particularly around medical decisions.

Just leave them [healthcare staff] to get on. [with medical decisions at end of life] [...] the longer you can keep it in their hierarchy the more success you're likely to have really. Is my view. (Person with dementia, 6)

People with dementia expected healthcare professionals to be knowledgeable and experienced when making care decisions. This trust in healthcare professionals appeared in part to stem from concerns that they would no longer be competent enough to make their own choices due to

cognitive deterioration. However some thought healthcare professionals should act in an advisory, rather than decision-making, capacity.

Because I think my choices for me care can't always be respected if it's not, the people concerned know it's not good for me. [...] because naturally people who are working with people that, that's had things like I have, and they know how to deal with it better than you do yourself. (Person with dementia, 5)

At least they [healthcare staff] give you help and advice, as to what's the best way to go. But at the end of the day, it's up to the individual as to what... if they want any further medical treatment or not. (Person with dementia 8)

Whilst carers expressed confidence in professionals and care staff to make important decisions regarding end of life care, they tended to focus decision-making in the delivery of daily care rather than specific medical decisions. They trusted that current good care would continue as needs changed and end of life approached.

I think [care home] will go out of their way, and I think they will, but where my mum's concerned, because of the way they treat her now, I know for a fact that if we come to that [end of life care], I know for a fact she'll be well looked after. (Current carer 7, Residential/nursing home 1)

... care plans have to be changed constantly to like what's going on. [...] They [service staff] were right on top of that stuff. I mean...I wasn't reading it. I was just signing it come the end. 'Cause, you had the confidence in the staff to know what was what, and they would just sort it out, you know. (Bereaved carer 2, Supported living service 1)

Fitting care together: Co-ordination and the role of families

Tensions between the views of people with dementia and carers also existed around the organisation of practical care at end of life. In addition to upholding their preferences and wishes and making important decisions, people with dementia also trusted that their families would be able to provide or arrange practical aspects of care as they deteriorated and their needs changed. This included working with services to ensure plans were enacted.

...the youngest one [daughter] [...], she is spot on and sharp and, and she would make sure I should, would have help. She is already looking after my affairs. (Person with dementia, 1)

So it's good to have the plan, but I also think you need the backup of your family, to see that the plan is implemented to its best outcome... (Person with dementia, 11)

Although carers wished to achieve this, some described encountering a range of organisational barriers to co-ordinating good end of life care. These included navigating complex systems to access continuing healthcare funding, pressure from service providers to move their relative into institutional care, and co-ordinating care providers from different services. These challenges were more apparent when trying to co-ordinate services to enable people to die in their own home.

The hardest part is actually trying – cos you end up the hub at the middle that's trying, in areas that you don't know what you're doing anyway, but trying to get it all to fit together.

(Bereaved carer 2, Supported living service 1)

Bereaved carers faced many practical and emotional aspects of care to manage at a time when they were potentially vulnerable. Some carers described the continued need for support in the co-ordination of care in the period soon after death. Examples included care staff carrying out practical tasks such as making phone calls to relatives and assisting with funeral arrangements. As well as reducing burden for newly bereaved carers at the beginning of the grieving process, this practical support also provided some emotional comfort.

... another friend was coming that afternoon and so [Manager] made that phone call for me, and I think she also phoned

[Husband]'s brother and he came straight away and also our very good friends [name], [Manager] made that phone call, so they were very good, you know, they did all the practical things, so that all worked out well. (Bereaved carer 3, Supported living service 1)

Discussion

Exploring the views of people with dementia and family carers on end of life care identifies important shared and divergent views. People with dementia and family carers agreed that maintaining preferred place of care, ensuring comfort and the provision of skilled professional carers were important. However a key inconsistency lay in the expectations of people with dementia that their families would be sufficiently confident and knowledgeable to act on their behalf whilst carers felt poorly prepared to fulfil this role.

Having a professional consensus framework on factors contributing to the delivery of optimal end of life care for people with dementia is key to informing policy and practice. However our study highlights the need to incorporate the perspectives of people with dementia and family carers into such recommendations, in order to ensure that such care is both person-centred and of optimal quality ²⁷. Comparisons of the views of people with dementia and family carers with expert professional consensus views ⁵,

highlighted interesting areas of agreement and discordance which have important implications for practice (Table 1).

In comparing the findings of our research with professional consensus, a key difference emerged around understanding of dementia as a palliative condition. As demonstrated through their perspectives on planning for the future, many people with dementia and carers did not recognise dementia as a palliative condition. This is unsurprising when, at both a policy and professional level, end of life care in dementia has been neglected²⁹. In contrast, the professional view emphasises the applicability of a palliative care approach towards dementia care throughout the disease trajectory (domains 1, 5 and 11). These different perspectives on dementia as a palliative condition are likely to contribute to the contrasting views expressed regarding the value and relevance of planning ahead. Whilst the professional view highlights the need to set care goals and engage in proactive advance planning (domain 3) and to avoid overly aggressive, burdensome or futile treatment (domain 6), people with dementia and family carers found it difficult to engage in such discussions in the abstract, particularly at earlier stages in the illness.

Further comparison with the professional view indicated subtle but important differences in emphasis even where there was broad agreement

on important components of end of life care. For example, in relation to continuity of care, people with dementia and family carers particularly emphasised the importance of maintaining their preferred place of care. The professional consensus focused instead on the importance of uninterrupted care even when transfers occur between settings, assisted by communication between caregivers (domain 4).

Similarly, the importance of skilled and competent staff in the delivery of good end of life care was emphasised by people with dementia and carers in this research and the expert consensus view (Domain 10). Whilst the consensus view takes a broad view which encompass needing the skills to meet all nine domains, our findings emphasise the skills which are specifically important to people with dementia and family carers.

Timely discussion of the person with dementia's views on future care was identified as a challenging area to enact in practice. Research has shown that older people tend to focus on the post-death period such as making funeral plans ^{18, 30}, rather than on the nature of their care prior to death. Older people in care homes, who are more likely to have cognitive impairment, often considered their affairs were 'sorted' and 'in order' ²⁰. People with dementia in this study shared these perspectives on planning ahead and additionally assumed that their family carers would intuitively

know their wishes. Although carers were more receptive to the concept of planning ahead, they felt uncomfortable and/or ill-prepared to undertake such responsibility and only with hindsight, often recognised that such planning would have helped with difficult end of life decisions ³¹. Worryingly, many healthcare professionals also feel equally ill-equipped to initiate future care planning conversations ^{11, 32}, especially in a proactive, rather than reactive, manner ³³. In theory, advance care planning is seen as fundamental to good palliative care, particularly in dementia, where capacity to make decisions may be compromised. There is however, limited evidence showing any significant difference to either patient/carer outcomes and/or resource use ³⁴. Although a recent systematic review has revealed it may be potentially cost effective ³⁵. In view of the many challenges identified in implementation, previous studies have shown there may be a need for staff with specific expertise in this area to ensure timely discussions and their outcomes are accurately documented and disseminated ^{5, 6}.

Previous research has highlighted concerns about a lack of co-ordination of care at end of life for people with dementia ^{9, 19, 24}. This contrasts markedly with the expectations of people with dementia in our study who were confident that an overall good standard of future care would be delivered,

but concurs with the experiences of bereaved carers. The confidence of people with dementia in their families' ability to co-ordinate and manage their care is at odds with carers' real life experience of needing, and sometimes failing to receive both practical and emotional support from professionals. In the UK, specialist palliative care nurses are a core component of usual cancer care and are often involved with a person with cancer from the point of diagnosis, supporting both the patient and their families. Similar specialist dementia nurses, for instance Admiral Nurses, exist but are not a core part of usual care and thus not widely available ³⁶.

Internationally there have been calls for a greater involvement of specialist palliative services in the care of older people with non-malignant conditions, but there is a lack of clarity on how to provide such care in light of our ageing populations and on whether a traditional hospice approach is appropriate ². ¹⁴. A recent UK study suggested a model of short-term, integrated palliative care, facilitated by a key worker, through usual care services ³⁷; although a lack of evidence of the effectiveness of palliative care assessments in dementia may hinder such future innovative models^{2, 14}.

Positive experiences and relationships with healthcare providers have been identified as vital to the experience of good end of life care in dementia ^{8, 24}, ^{38, 39}. However, negative factors also impact on care quality ³⁸. Interestingly,

people with dementia were confident that their future care providers would be both professionally competent and innately compassionate to deliver end of life care. Family carers highly valued a person-centred approach to care, but recognised that compassion was not always standard. In the UK, medical training in dementia is very limited at an undergraduate level ^{40, 41}. Family doctors, the main healthcare providers at the end of life, lack both knowledge and confidence in providing care in general to people with dementia ⁴², although this may be improving ⁴³. It would appear that additional support and/or training is still required in certain challenging areas such as discussing the palliative nature of dementia, planning ahead for future care and providing both emotional and practical support to families.

Strengths and limitations

Our interviews with people with dementia were conducted after they had undertaken a Q-sort exercise in which they ranked 24 pre-generated statements about end of life care. Participation in this exercise appeared to facilitate the interviews and may have helped to set the scene to further explore their personal views in more detail. However, topics discussed during participation in the Q-sort exercise may have influenced responses. Also, we cannot assume that the views of people in the early stages of

dementia accurately represent those in the more advanced stages of the condition. Qualitative interviews are inappropriate for seeking the views of people with advanced dementia ⁴⁴. We decided, therefore, to focus on people with earlier stage dementia to maximise the quality and trustworthiness of the data.

Although death is not a taboo subject for people dying with dementia ¹⁸, those participating in this research did not consider themselves to be approaching the end of life and thus were discussing this aspect of care from a hypothetical perspective. However, with few exceptions, people with dementia could consider their future possible needs, although this may be dependent on different hypothetical health states ⁴⁵. People with dementia were recruited from the community, and from one area of England, rather than through healthcare services. Therefore the views of people with dementia living in residential care or people with dementia without family carers and regional variation were not captured. In addition, the results could not be cross checked in family dyads and the impact of gender issues were not explored. Consequently, these limitations may impact on the generalisability of the findings to more diverse populations. However, despite these limitations, this study addresses a critical research gap by directly seeking the views of people with dementia themselves on end of life care rather than only the seeking a proxy view from relatives after death ²³,

⁴⁶, or relying on interpretations represented by family caregivers ⁴⁷, which may be misinterpreted.

Seeking the views of both current and bereaved carers provided a more balanced perspective between expectations and experience of end of life dementia care. Bereaved carers openly discussed end of life care, however a small number of current carers struggled to engage in discussions around end of life care. These carers found it difficult to think about the death of their relative. However, it has been suggested that research participation may open up opportunities for such discussions to begin in real life ³⁰.

Implications for policy, future practice and research

End of life care for people with dementia has been neglected at both a policy and professional level ²⁹. Our study identifies key divergent perspectives of people with dementia and family carers on factors contributing to optimal end of life care. It also highlights important discrepancies between the perspectives of people with dementia and family carers and the published consensus views of professionals. Policy and practice must therefore reflect the varied perspectives of different stakeholder groups. People with dementia were confident that their families would co-ordinate and manage their care as required, however carers found this difficult in practice. While in the UK cancer patients have access to specialist nurses from the point of

diagnosis, who can assist with co-ordinating care, similar specialist dementia nurses (Admiral Nurses) are not a core part of usual care and thus not widely available ³⁶

Our study identifies specific areas where additional resources, support or training may be required to improve the delivery of better quality care towards and at the end of life for people with dementia. Examples include: better education for people with dementia and families about dementia and its prognosis ⁴⁸; involving palliative care expertise earlier in the dementia pathway ³⁷, especially in terms of emotional support around making difficult decisions ¹⁷; and developing a specialist dementia nurse or 'care co-ordinator' to address the areas of particular difficulty identified by this study ⁴⁹. We suggest that further research is needed to: i) identify how best to seek the views of people in different stages of dementia about such a sensitive and potentially distressing topic as end of life; ii) explore approaches to improve understanding of dementia as a palliative condition with people with dementia and family carers and iii) determine how interventions such as advance care planning can be more appropriately and effectively integrated into usual dementia care.

Acknowledgements

This paper details the findings of research conducted as part of the Supporting Excellence in End of life care in Dementia (SEED) programme funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (RP-PG-0611-20005).

We are extremely grateful to the people with dementia and family carers who so readily gave their time to take part. We would also like to acknowledge the work of our colleagues in SEED Workstream 1.3 team, in particular Sarah Hill who conducted the Q-sort exercise alongside the qualitative interviews.

Funding

This report summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grant for Applied Research Programme (Grant Reference Number RP-PG-0611-20005). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Declaration of conflict of interest

The authors declare that there is no conflict of interest.

Research ethics

Ethical approval for the research was granted by NRES Committee North East - Newcastle & North Tyneside 1 (13/NE/0335).

Authorship

MP drafted and revised the article, made a substantial contribution to the concept of the article, data collection, analysis and interpretation of data.

CB revised the article, made a substantial contribution to the concept of the article, study design, data collection, analysis and interpretation of data. EM revised the article, made a substantial contribution to the concept of the article, data collection, analysis and interpretation of data.

RPL made a substantial contribution to the concept of the article, data collection, analysis and interpretation of data. CE made a substantial contribution to the concept of the article, study design, data collection, analysis and interpretation of data. JCH made a substantial contribution to the study design and critically revised the article for important intellectual content. KHD made a substantial contribution to the study design and critically revised the article for important intellectual content. LR is lead investigator; made a substantial contribution to the concept of the article, study design, interpretation of the data and critically revised the article for important intellectual content.

References

1. Alzheimer's Disease International. World Alzheimer Report 2015: The Global Impact of Dementia: an Analysis of Prevalence, Incidence, Cost and Trends. London: Alzheimer's Disease International, 2015.
2. World Health Organization. Palliative care for older people: better practices. In: Hall S, Petkova H, Tsouros AD, Costantini M and Higginson IJ, (eds.). Copenhagen: World Health Organization, Regional Office for Europe, 2011.
3. Alzheimer's Disease International. World Alzheimer Report 2011. The benefits of early diagnosis and intervention. London: Alzheimer's Disease International, 2011.
4. Department of Health. Living Well with Dementia: A National Strategy. London 2009.
5. Van der Steen J, Radbruch L, Hertogh C, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014; 28: 197-209.
6. National Institute for Clinical Excellence. End of life care for people with dementia London: NICE, 2010.
7. Thune-Boyle I, Sampson E, Jones L, King M, Lee D and Blanchard M. Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia.* 2010; 9: 259-84.
8. Davies N, Maio L, Rait G and Iliffe S. Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis. *Palliat Med.* 2014; 28: 919-30.
9. Van der Steen J. Dying with dementia: What we know after more than a decade of research. *J Alzheimers Dis.* 2010; 22: 37-55.
10. Amador S, Sampson E, Goodman C and Robinson L. Quality indicators for palliative care: How useful are they for the assessment of end-of-life care in dementia? *J Am Geriatr Soc.*
11. Dickinson C, Bamford C, Exley C, Emmett C, Hughes J and Robinson L. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *Int Psychogeriatr.* 2013; 25: 2011-21.
12. Birchley G, Jones K, Huxtable R, Dixon J, Kitzinger J and Clare L. Dying well with reduced agency: a scoping review and thematic synthesis of the decision-making process in dementia, traumatic brain injury and frailty. *BMC Med Ethics.* 2016; 17: 46.

13. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD and Deliëns L. Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc.* 2010; 58.
14. Leadership Alliance for the Care of Dying People. One chance to get it right: Improving people's experience of care in the last few days and hours of life. London: NHS England, 2014.
15. Robinson L, Dickinson C, Bamford C, Clark A, Hughes J and Exley C. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but... ' *Palliat Med.* 2012; 27: 401-8.
16. Thoresen L, Ahlzén R and Solbrække KN. Advance Care Planning in Norwegian nursing homes—Who is it for? *J Aging Stud.* 2016; 38: 16-26.
17. Brazil K, Galway K, Carter G and van der Steen JT. Providing Optimal Palliative Care for Persons Living with Dementia: A Comparison of Physician Perceptions in the Netherlands and the United Kingdom. *J Palliat Med.* 2017; 20: 473-7.
18. Godwin B and Waters H. 'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers. *Mortality.* 2009; 14: 265-85.
19. Dening KH, Jones L and Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med.* 2013; 27: 409-17.
20. Mathie E, Goodman C, Crang C, et al. An uncertain future: The unchanging views of care home residents about living and dying. *Palliat Med.* 2011.
21. Hennings J, Froggatt K and Keady J. Approaching the end of life and dying with dementia in care homes: the accounts of family carers. *Rev Clin Gerontol.* 2010; 20: 114-27.
22. Alzheimer's Society. My life until the end: Dying well with dementia. London: Alzheimer's Society, 2012.
23. Kutner JS, Bryant LL, Beaty BL and Fairclough DL. Symptom distress and quality-of-life assessment at the end of life: the role of proxy response. *J Pain Symptom Manage.* 2006; 32: 300-10.
24. Alzheimer's Disease International. World Alzheimer Report 2016. Improving healthcare for people living with dementia: coverage, quality and costs now and in the future. London 2016.
25. Berger TL and Luckmann T. *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* London: Sage, 1967.
26. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007; 19: 349-57.

27. Hill SR, Mason H, Poole M, Vale L, Robinson L and on behalf of the Seed team. What is important at the end of life for people with dementia? The views of people with dementia and their carers. *Int J Geriatr Psychiatry*. 2016.
28. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006; 3: 77-101.
29. Nakanishi M, Nakashima T, Shindo Y, et al. An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper. *Int Psychogeriatr*. 2015; 27: 1551-61.
30. Seymour J, Gott M, Bellamy G, Ahmedzai SH and Clark D. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med*. 2004; 59: 57-68.
31. Harrison-Dening K, King M, Jones L and Sampson EL. Healthcare decision-making: past present and future, in light of a diagnosis of dementia. *Int J Palliat Nurs*. 2016; 23: 4-11.
32. Van der Steen JT, Galway K, Carter G and Brazil K. Initiating advance care planning on end-of-life issues in dementia: Ambiguity among UK and Dutch physicians. *Arch Gerontol Geriatr*. 2016; 65: 225-30.
33. Van Soest-Poortvliet MC, Van der Steen JT, Gutschow G, et al. Advance care planning in nursing home patients with dementia: a qualitative interview study among family and professional caregivers. *J Am Med Dir Assoc*. 2015; 16: 979-89.
34. Robinson L, Dickinson C, Rousseau N, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing*. 2012; 41: 263-9.
35. Dixon J, Matosevic T and Knapp M. The economic case for advance care planning: a systematic review. *Palliat Med*. 2015; 29: 869-84.
36. Evans SC, Harrison-Dening K and Read K. Towards the end of life: An in-depth exploration of the role of Admiral Nursing in dementia care (Innovative practice). *Dementia*. 2016: 1471301216636485.
37. Bone AE, Morgan M, Maddocks M, et al. Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders. *Age Ageing*. 2016: 1-10.
38. Lawrence V, Samsi K, Murray J, Harari D and Banerjee S. Dying well with dementia: qualitative examination of end-of-life care. *Br J Psychiatry*. 2011; 199: 417-22.
39. Caron CD, Griffith J and Arcand M. Decision making at the end of life in dementia: How family caregivers perceive their interactions with health

- care providers in long-term-care settings. *J Appl Gerontol*. 2005; 24: 231-47.
40. Tullo E and Allan L. What should we be teaching medical students about dementia? *Int Psychogeriatr*. 2011; 23: 1044-50.
41. Tullo E, Spencer J and Allan L. Systematic review: helping the young to understand the old. Teaching interventions in geriatrics to improve the knowledge, skills and attitudes of undergraduate medical students. *J Am Geriatr Soc*. 2010; 58: 1987-93.
42. Turner S, Illiffe S, Downs M, et al. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age Ageing*. 2004; 33: 461-7.
43. Tang E, Birdi R and Robinson L. Attitudes to diagnosis and management in dementia care: views of future general practitioners. *Int Psychogeriatr*. 2016: 1-6.
44. Cowdell F. Engaging older people with dementia in research: myth or possibility. *Int J Older People Nurs*. 2008; 3: 29-34.
45. Harrison-Dening K, King M, Jones L, Vickestaff V and Sampson EL. Advance care planning in dementia: Do family carers know the treatment preferences of people with early dementia? *PLoS One*. 2016; 11.
46. Addington-Hall JM and McPherson C. After-death interviews with surrogate/bereaved family members: some issues of validity. *J Pain Symptom Manage*. 2001; 22: 784-90.
47. Russell C, Middleton H and Shanley C. Research: Dying with dementia: The views of family caregivers about quality of life. *Australas J Ageing*. 2008; 27: 89-92.
48. Arcand M, Brazil K, Nakanishi M, et al. Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France, and Japan. *Int J Palliat Nurs*. 2013; 19: 67-74.
49. Hughes JC, Robinson L and Volicer L. Specialist palliative care in dementia: specialised units with outreach and liaison are needed. *Br Med J*. 2005; 330: 57-8.

