RESEARCH ARTICLE

International Journal of Geriatric Psychiatry

What is important at the end of life for people with dementia? The views of people with dementia and their carers

Sarah R. Hill[1], Helen Mason[2], Marie Poole[1], Luke Vale[1], Louise Robinson[1] and on behalf of the SEED team

[1]Newcastle University, Newcastle upon Tyne, UK
[2]Glasgow Caledonian University, Glasgow, UK
Correspondence to: S. Hill. E-mail: s.r.hill2@newcastle.ac.uk

Background: Approaching end of life is often a time of vulnerability; this is particularly so for people with dementia and their families where loss of capacity and the ability to communicate, make assessment and shared decision-making difficult. Research has consistently shown that improvements in care and services are required to support better quality and more person-centred care for people with dementia towards and at end of life. However, the views of people with dementia about what factors contribute to high-quality care at this time are a neglected area.

Aim: The aim of this study was to identify the aspects of end-of-life care for people with dementia that are most important to them and their carers.

Design: Q-methodology, a mixed method combining qualitative and quantitative techniques to study subjectivity, was used to identify the views of people with mild dementia, their family carers and bereaved carers on end-of-life care for people with dementia. Fifty-seven participants were included in the study.

Results: Four distinct views were identified: family involvement, living in the present, pragmatic expectations and autonomy and individuality. Some areas of consensus across all views included compassionate care, decisions being made by healthcare professionals and information availability when making decisions.

Conclusion: Our findings reveal several different views on what is important about end-of-life care for people with dementia; therefore, a 'one-size-fits-all' approach to care is unlikely to be most appropriate. Notwithstanding the differing viewpoints could provide a framework for service providers and commissioners for future care. Copyright © 2016 John Wiley & Sons, Ltd.

Key words: dementia; end-of-life care; Q-methodology; Q-sort; decision-making
History: Received 13 April 2016; Revised 12 July 2016; Accepted 14 July 2016; Published online in Wiley Online Library (wileyonlinelibrary.com)
DOI: 10.1002/gps.4564

Introduction

The need for high-quality, compassionate care for people and their families, especially at their most vulnerable moments, such as towards and at the end of life (EoL), is well-recognised internationally (World Health Organization, 2011; Department of Health, 2012; van der Steen *et al.*, 2014). Delivering EoL care is particularly challenging in dementia where issues such as impaired mental capacity and communication skills can make it difficult to provide high quality, person centred care (Robinson *et al.*, 2005; van der Steen *et al.*, 2014). Difficulties in prognostication, failure to recognise dementia as a terminal illness and failure to initiate future care planning discussions, whilst the person with dementia has capacity that also contribute to these difficulties (Mitchell *et al.*, 2004; Thuné-Boyle *et al.*, 2010; Dickinson *et al.*, 2013; Robinson *et al.*, 2013). Research has shown specific areas in need of improvement include symptom control (Hendriks *et al.*, 2014); the need for better services to enable dying at home or hospice care (Treloar *et al.*, 2009); and the provision of compassionate care (Crowther *et al.*, 2013).

Exploring the views and preferences of all stakeholders involved in EoL care in dementia is necessary to evaluate current provision and inform how care can be improved. Often, the perspectives, experiences and opinions sought are those of family carers (Treloar *et al.*, 2009; Hennings *et al.*, 2010; Davies *et al.*, 2014a), healthcare professionals (Livingston *et al.*, 2012; Davies *et al.*, 2014b; Lee *et al.*, 2015) or sometimes both (Thuné-Boyle *et al.*, 2010; Lawrence *et al.*, 2011; Raymond *et al.*, 2014), but it is also important to seek the views of those who are in receipt of EoL care. Some initial work has been undertaken with people with dementia and their carers to explore whether they were able to generate and prioritise preferences for EoL care (Dening *et al.*, 2013). The aim of this study was to further build upon these initial findings, using Q-methodology to identify and describe the views shared by people with dementia, current family carers and bereaved carers about the elements of care considered important towards and at EoL.

Methods

Q-methodology is an approach that combines qualitative and quantitative techniques to study subjective areas (Baker *et al.*, 2006; Watts and Stenner, 2012) and thus was applied to obtain the subjective views of the people with dementia and carers. This method provides a way to understand participant views on what is important to them about the care services they receive and enabled the team to elicit features, which are important to certain groups of participants and not others or alternatively what is important (or unimportant) in consensus.

The stages of a Q-study are described in detail elsewhere (Watts and Stenner, 2012); therefore, only a summary is provided here. The first stage of a Q-study is to develop the concourse that represents all of the possible views on the topic in question (Brown, 1980). As this concourse can be very large, it is necessary to sample from this to derive a smaller (but still representative) set of statements (Q-set). The second stage is the Q-sort; here, each individual respondent provides their point of view by rank ordering the statements (usually according to agreement). Following the Q-sorting exercise, a form of 'by-person' factor analysis is conducted. This analysis groups together similar Q-sorts to reveal a small number of underlying perspectives, which are referred to as factors. Through interpretation of the factors, rich descriptions of different points of view are generated (Mason *et al.*, 2011).

Details of the stages of this Q-study can be found in Table 1.

Study sample and setting

Sampling in Q-methodology is purposive, seeking to recruit respondents that may hold different views on the topic to identify the different, shared views that exist (Brown, 1980). Three key groups of respondents were recruited to obtain a diverse range of perspectives and experiences: people with early-stage dementia, family carers and bereaved family carers. The inclusion criteria for family and bereaved carers was as follows: non-professional carers of a person with dementia who are either a member of family, spouse or a friend and family carers of a person with dementia who had died a minimum of 3 months prior to contact, respectively. Because of the nature of study topic and the cognitive demands of the Q-sort exercise, it was considered inappropriate to engage with people in more advanced stages of dementia. Therefore, the sample population was limited to individuals with mild dementia, for whom the Q-sort could be an appropriate and engaging tool to elicit their views (Forrest, 2010).

Participants were identified through the Dementias and Neurodegenerative Diseases Research Network,[1] Join Dementia Research [2] and VOICENorth.[3] A representative from the organisation used clinical records to ensure that the participants were in the earlier stages of dementia (determined by a dementia diagnosis in the past 3 years and/or, where available, a mini-mental state examination score >20) before they were approached about the study. Mental capacity to participate in the research was assessed by researchers and written consent obtained.

A separate set of statements was created for people with dementia. These were written in the first person (Table 2), whilst the statements for carers were written in the third person and referred specifically to their relation to the person with dementia (Table S1); the statements were piloted to ensure the terminology used and statement length was appropriate.

[1]https://www.crn.nihr.ac.uk/dementia/
[2]https://www.joindementiaresearch.nihr.ac.uk/
[3]http://www.ncl.ac.uk/ageing/partners/voicenorth/#about

Table 1 Description of each stage of the Q-study in detail

Stages	Steps
Concourse generation (102 items)	• Conduct an in-depth search of academic literature relative to dementia care, palliative care and EoL care to identify a range of aspects of EoL care for people with dementia. • Search relevant guidance documents (National Collaborating Centre for Mental Health, 2007; Sampson *et al.,* 2009) • Conduct an online media search of news articles and dementia organisations' websites. • Examine transcripts from interviews with national experts in dementia care.
Q-set generation (24 statements)	• Condense the concourse using a framework based on the 'eight domains of palliative care' (NCP, 2009). • Categorise each concourse item according to the framework and merge similar statements. • Sample statements to ensure coverage of all of eight domains. • Pilot test 23 statements with a patient and public involvement group to further refine the statements and add anything that was considered missing. • Map the statements onto a 'conceptual framework' of outcomes and indicators of good-quality care (Amador *et al.,* 2015) resulting in a final set of 24 statements (Table 2).
Administering the Q-sort	• Present each statement to the participant on a separate, numbered card. • Ask the participant to think about what is important to them about EoL care for a person with 'memory problems'. • Instruct the participant to sort the statements into three piles: most important, quite important and least important; advise the participant to place any statements he or she disagrees with in the least important pile. • Invite the participant to rank order the cards onto a grid (Figure 1) starting with the 'most important' statements through to those that were 'least important'. • Conduct a short 'post-sort' interview with the participant to identify the reasoning behind their choices of most and least important statements and further explore their opinions. This also facilitated verification of their sorting and ranking choices.
Data analysis and interpretation	• Individual Q-sorts were entered into a specialist software package, PQ Method (Schmolck, 2002), and a 'by–person' factor analysis (Centroid factor analysis followed by Varimax rotation) was conducted. • The factor analysis identified clusters of respondents who completed the Q-sort in a similar way (Watts and Stenner, 2012), and these clusters define the different factors. • The decision on the number of factors to retain for interpretation was based on an examination of the Eigen values, the number of participants significantly correlated with each factor, the percentage explained variance and the post sort qualitative comments. • Each factor was interpreted by first examining the idealised Q-sort of each factor (which describes how a person who perfectly correlates with the factor would have laid out their 24 statements) with reference to the relative position of statements within and between factors. • Particular attention was given to the statements placed at the top and bottom rows of the Q-sort and distinguishing statements that have a significantly different ($p < 0.01$) position in the idealised Q-sort compared with the other factors. • The responses from the 'post-sort' qualitative interviews with respondents were used to help provide connections or explain the positioning of statements.

Ethics approval was granted by the NRES Committee North East on 19/12/2013, REC reference: 13/NE/0335.

Results

In total, 57 people participated in the Q-sort, 14 people with dementia, 21 carers and 22 bereaved carers.

Factor analysis revealed four factors comprising different shared viewpoints on what is important about EoL care for a person with dementia (Table 2). These factors were developed from 39 of the 57 Q-sorts, as 18 Q-sorts were not significantly correlated with any factor. The four factors altogether account for 49% of the total variance (F1 12%, F2 17%, F3 8%, F4 12%) between the 57 Q-sorts.

Factor 1: family involvement

The close relationship between family carers and their relative with dementia places carers in a good position to make decisions for their relative if he or she no longer can. This is viewed as being preferable to leaving important medical decisions to healthcare staff; to facilitate this, it was considered essential to have a plan in place for their care which documents their wishes 'it's really important to know that ahead of time so that we can plan for it and respect her wishes' (29C).

Family carers do not see caring for their relative as a burden but as a part of their relationship that they enjoy; therefore, carers do not see moving the person with dementia to a care home an important option. It is more important to keep the person with dementia in their own home, or usual place of care and have the family with them at the EoL. Most importantly, the

Table 2 The placement of each statement within the idealised Q-sorts for each factor where '3' = *most important* and '−3' = *least important*

No.	Statement	F1	F2	F3	F4
1	My opinions and choices for my care should be respected.	1	−1	0	2
2	I should be able to continue with my hobbies and interests in the last year of my life.	0	**−3**	1	1
3	Paid carers and family carers should take account of my spiritual or cultural beliefs in all caring duties.	1	**−3**	−1	−2
4	Paid carers should be trained to notice if I am in pain.	2	2	1	0
5	I would like to have family/friends with me at the very end of life.	2	2	−2	**3**
6	I would like to have a plan in place for what care I would like to receive at the end of my life when I might not be able to clearly express myself.	**3**	−2	0	2
7	My care plans for end-of-life care should be regularly checked by paid and family carers in case I want to make any changes.	0	−2	−2	−1
8	I should be helped to take my medication even if I forget what it's for.	1	1	2	−1
9	Paid carers and family carers should help me eat only if I want to.	−1	−1	0	−2
10	Important medical decisions about my end-of-life care should be left to healthcare staff.	**−3**	0	**−3**	**−3**
11	My family should make decisions about my end-of-life care if I no longer can.	2	1	−2	2
12	I would move to a care home if it becomes too much for my family/friends to look after me.	−2	0	**3**	0
13	I would like to be able to receive the majority of the care I need at the same location (e.g. in my own home or care home).	0	2	2	1
14	I would like my family to be told about how my needs and care will change over time.	0	0	−1	0
15	Short stays in respite care should be available to give my family/friends a break from caring.	−2	0	0	0
16	Paid carers should be trained how to give me my medication.	−1	1	1	−1
17	My day to day care should be regularly discussed by family carers, paid carers and me.	−1	0	−1	0
18	I should have help to put my affairs in order and make preparations.	−2	−1	0	**−3**
19	Care should be taken to find the cause of any distress which may affect me.	1	**3**	2	1
20	Hospice care should be more available to me.	**−3**	−2	−1	0
21	I should be cared for with compassion.	**3**	**3**	**3**	**3**
22	Support should be available for my family after I pass away.	0	−1	**−3**	−2
23	Care homes should allow me to keep personal things in my room to make it homely.	−1	0	0	−1
24	When I or my family have to make decisions about my care, there should be someone who can provide us with information to help us.	0	1	1	1

The 'most important' and 'least important' statements in each idealised factor are highlighted in bold.

person with dementia should be cared for compassionately through understanding and acknowledgement of their needs and wishes.

One person with dementia, four current carers and three bereaved carers form this factor (Table 3).

Factor 2: living in the present

A day-to-day approach for the care of people with dementia is expressed in this factor, tackling challenges as they appear. Planning for EoL is not of high importance, people with dementia would prefer to focus on the present. It is more important that the correct processes are in place to ensure the comfort and safety of the person with dementia at the end of their life, for example, identifying any distress, having responsible carers trained to identify pain and, most importantly, compassionate care for the person with dementia. Carers wished to include a level of physical and tactile comfort for their relative with dementia, 'I think she could do with a little more feel and touch' (11C). It is also important that the person with dementia receives care in the same location, so that he or she is comfortable in familiar surroundings.

Family carers recognise the changes in the abilities and interests of their relative with dementia. Carers respect these changes, which are reflected in the view that enabling their relative to continue taking part in hobbies and interests in their last year of life is least important. Similarly, respecting spiritual/cultural beliefs is not considered important as there were perceptions that the person with dementia may no longer be able to engage in maintaining their spirituality and beliefs.

One person with dementia, six carers and eight bereaved carers form this factor

Factor 3: pragmatic expectations

This factor was characterised by two diametrically opposed viewpoints in that statements were placed in a similar pattern but at the opposite ends of the grid (Figure 1); the majority view is taken as the main viewpoint; however, the 'mirror-image' viewpoint, prescribed to by the two participants with dementia only, is also presented.

The main viewpoint

Family carers take a pragmatic approach to EoL care for people with dementia. They acknowledge their limitations as relatives, prioritising above all provision of the 'best care'. Ensuring the person with dementia's health and safety through compassionate care is of utmost importance even if this involves a move to a care home where trained staff can provide specific support. Wherever the person with dementia lives, it is important that he or she receives the majority of care in that location to minimise distress from being moved away from a place of familiarity.

Family involvement in making decisions is less important, but carers would still not feel comfortable leaving important care decisions entirely to healthcare professionals and would like relevant input. Family carers acknowledge that the person with dementia may not recognise the family at the very EoL; therefore, being present at this time is not very important.

Table 3 Demographic details of participants in each factor

			Factor 1	Factor 2	Factor 3	Factor 4
People with dementia	*N*		1	1	2	4
	Mean age (median), years		78.0 (78.0)	74.0 (74.0)	74.0 (74.0)	65.5 (64.0)
	Mean time since dementia diagnosis (median), years		3 (3)	6 (6)	3.5 (3.5)	1.5 (1.5)
Carers	*N*		4	6	1	4
	Relationship to person with dementia	Wife	3	2	–	2
		Husband	–	1	–	–
		Son	–	1	–	1
		Daughter	1	2	1	–
		Other	–	–	–	1
Bereaved Carers	*N*		3	8	2	3
	Mean time since bereavement (median), months[a]		26.7 (34.0)	25.9 (28.5)	10.5 (10.5)	24.3 (18.0)
	Relationship to person with dementia	Wife	1	5	–	1
		Husband	–	2	1	1
		Son	1	–	1	–
		Daughter	1	1	–	–
		Other	–	–	–	1

[a]Rounded to the nearest 1d.p.

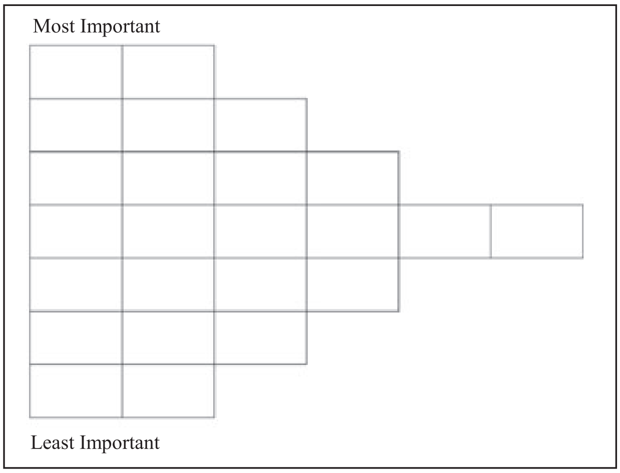

Figure 1 The Q-grid used with participants (scaled down).

Once the person with dementia has passed away, families do not feel support would be important; they see death as an inevitability and grief to be dealt with within the family circle; 'at the end of the day it's a death…families tend to know…the protocol' (14C).

The 'mirror-image' viewpoint

The statements placed at the extremes of the Q-grid, described in the following sections, highlight the contrast between the main and 'mirror-image' viewpoints.

Planning for future care is not important to people with dementia; they certainly do not want plans 'pushed in [their] face' (18D). It is least important that care is provided in the same location, and moving to a care home is not considered a priority.

This viewpoint regards healthcare professionals making medical decisions most important, whilst also considering important the family making decisions for the person with dementia. Another contrast to the main viewpoint is the opinion about support for families after the death of the person with dementia, which is regarded most important.

Finally, compassionate care, which is prioritised by the main viewpoint and all other factors, is considered less important by the 'mirror-image' view.

One carer, two bereaved carers and two people with dementia form this factor.

Factor 4: autonomy and individuality

People with dementia in this factor, value a significant level of autonomy and individuality for their EoL care, with their opinions and choices respected and the ability to put a plan in place for their care at the EoL; 'it's important the power and control are with the person [with dementia]' (13C). Should the person with dementia become unable to do this, they wish their family to make decisions on their behalf according to their wishes and not leave them to healthcare staff. Compassionate care is essential and incorporates respect for the person with dementia as an individual. Maintaining hobbies and interests at the EoL is also considered an important means of allowing the person with dementia to express their individuality.

Independence in self-care is important for the person with dementia; therefore, help with tasks such as taking medication and eating is not prioritised. In this factor, people with dementia do not feel that it is necessary to receive help putting their affairs in order as they are confident that this will be performed at a stage in their life where they are capable of managing this themselves. Whilst remaining independent for as long as possible is imperative to the person with dementia, having family and friends with them at the very EoL is still a comfort they rate highly.

Four people with dementia, four carers and two bereaved form this factor.

Consensus statements

Linking the four factors described previously, were three 'consensus statements' which appeared in the same position across all or most of the idealised Q-sorts of each factor. These common views suggest that there are areas of EoL care which are of key importance amongst a diverse range of views. These consensus statements included: #21 'I should be cared for with compassion'; #10 'Important medical decisions about my EoL care should be left to health care staff' and #24 'When I or my family have to make decisions about my care, there should be someone who can provide us with information to help us' (Table 2). In summary, participants felt compassion and supported shared decision-making were fundamental aspects of EoL care for people with dementia and their families.

Discussion

This is the first study to use a specific methodology, Q, to directly elicit the views of people with dementia, and their carers, about the sensitive subject of EoL care. Four different shared viewpoints on what is important to the participants about this aspect of care emerged. The most prominent conclusion to be drawn from the Q-sort is that, there are multiple perspectives of good EoL care for people with dementia; and thus, a 'one-size-fits-all' approach to planning is not appropriate to accommodate individual needs. This finding has implications for practitioners who in clinical care are often required to follow evidence-based guidance to ensure good-quality EoL care (NICE, 2015) which may detract from an individualised, person-centred approach. Whilst it is important that practitioners follow established guidelines, the results of this study suggest that this should not be at the expense of providing care to fit the specific needs and wishes of the individuals involved and practitioners should, therefore, be adaptable in their approach to EoL care for people with dementia.

Whilst the main finding of this study implies variation amongst views of the elements of EoL care that are important to people with dementia and their carers, the 'consensus' statements (#21, #10 and #24; Table 2) that are common to each factor do reflect some convergence of views about key aspects of EoL care. The first consensus statement, #21 'I should be cared for with compassion', was placed as the most important in all factors. Our findings indicate that participants perceived compassion uniquely in each of the different factors. Whilst compassion may be considered fundamental to EoL care for people with dementia, the provision of compassionate care can be challenging (Department of Health, 2012; Crowther *et al.*, 2013). Previously identified barriers to providing compassionate care include: professionals who are desensitised to the needs of individuals often through working in target-driven environments (Crowther *et al.*, 2013), reflecting organisational pressures (Davies and Iliffe, 2014) and more deeply rooted cultural factors (Kellehear, 2013). Whilst our findings cannot directly address these challenges, they do further highlight the importance of the provision of compassionate care through a person-centred approach with a focus on understanding and respecting the person's needs and wishes, good, safe care and a tactile and empathetic approach.

The second consensus statement, #10 'Important medical decisions about my end-of-life care should be left to health care staff', was considered least important for the majority of factors (with the exception of factor 2 which viewed it as 'quite important'). Participants who placed the statement 'least important' actively disagreed with it. The majority view is that family members should have some say in medical decisions about the person with dementia and not leave it solely in the hands of health care staff as they have intimate knowledge of the *person* with dementia's wishes. Enabling family involvement in decision-making is also underpinned by the third consensus statement, #24 (Table 2). Current UK guidance (Nuffield Council on Bioethics, 2009) recommends healthcare professionals engage with carers and family members to facilitate joint decision-making when the person with dementia experiences difficulties in expressing their wishes; previous research however reveals that relatives may feel ill-equipped or unable to do this on their relatives behalf (Raymond *et al.*, 2014).

The remaining factors each represent a viewpoint shared by a mix of carers and people with dementia. The main aspects of EoL care that differ between the factors are as follows: planning ahead, responsibility for decision-making and moving to a care home versus remaining at home. Another barrier to shared decision-making and the provision of high-quality EoL care is the ability of both the public and health professionals to have open and honest discussions about death and dying. In dementia, healthcare professionals struggle to initiate and undertake such sensitive discussions about future care planning at an early stage in the dementia trajectory, whilst the person is able to play an active role (Dickinson *et al.*, 2013; Robinson *et al.*, 2013). This makes involvement in shared decision-making particularly challenging (NHS - End of Life Care Programme, 2010). Shared decision-making is also a cornerstone of Advanced Care Planning which has been shown to prevent unnecessary hospital admissions for people with advanced dementia by facilitating better quality, person centred care for people with dementia (Robinson *et al.*, 2012; Ampe *et al.*, 2015).

Strengths and limitations

To date, the use of Q-methodology to establish the views of people with dementia is relatively novel (Forrest, 2010; Westbrook *et al.*, 2013). A Q-sort facilitates exploration of sensitive topics, such as EoL care, that may be difficult to discuss openly in society (Department of Health, 2008). Participants in a Q-study have to prioritise aspects; therefore, some level of relative preference can be identified using this method and the qualitative post-sort interviews strengthen interpretation of the viewpoints. However, one limitation is that due to our approach to sample selection, our findings may not be generalizable. The research databases we used to identify potential participants are established via an opt-in approach; therefore, our sample comprises people with dementia who are positive about engagement in research. Also, we excluded participants with advanced stage dementia thus, potentially missing views from the very group who would be in receipt of EoL care. However, this research does not claim to contain an exhaustive range of viewpoints.

In addition, interpretation of the factors was also influenced by the fact that the two participants with dementia prescribing to the 'mirror-image' view of factor 3 were unable to complete a post-sort interview. Limited qualitative data was therefore available to aid the interpretation of this viewpoint; the only available supplementary data were field notes taken by researchers during the card sorting process.

The post-sort interview provided a means of validating the Q-sorts by allowing participants to justify their choices. However, the validation method could be improved. A method used in a Q-sort study conducted with participants with severe intellectual disabilities was identified post data collection (Cramm *et al.,* 2009). This method, whilst not used with participants with dementia, could be a useful tool for validating Q-sorts administered with this population in future work.

Finally, our sample of participants with dementia was relatively small compared with the other groups which was a result of practical limitations in recruiting participants from this population. Of the 14 Q-sorts belonging to people with dementia, 6 (43%) did not load significantly onto a factor which potentially indicates that data saturation was not reached with this group. It is therefore possible that further study in this area, with a larger sample of participants with dementia, would identify additional viewpoints not captured here.

Conclusion

There is a plurality of views on what is considered important by people with dementia and their families with regard to end-of-life care. Four different viewpoints were identified by this study: family involvement, managing the present, pragmatic expectations and autonomy and independence. This variety in viewpoints indicates that there is no universal opinion on what is important about EoL care for people with dementia; therefore, when considering how best to improve care a 'one-size-fits-all' approach is unlikely to be most appropriate. This has implications for real world practice where clinicians are often required to follow national evidence-based guidelines which if applied to formulaically may interfere with providing individual person-centred care. In light of the findings from this study, practitioners should therefore be mindful of tailoring guidance to the needs of the individual. The Q-sort did however also identify several elements of consensus such as: prioritising compassionate care, family involvement in medical decision-making alongside healthcare staff and having someone help families make decisions. Whilst the views identified by this study may not be exhaustive, they are a good starting point for future research into this area and identify elements of care that should be focused on to improve EoL care for people with dementia.

Acknowledgements

The authors would like to thank the Dementias and Neurodegenerative Diseases Research Network, Join Dementia Research and VOICENorth for their role in recruiting participants to the study. We would also like to thank Dr Richard Lee from the Institute of Health and Society, Newcastle University, for his assistance with data collection and all participants in the study who gave their time to take part in our research. This article presents independent research funded by the National Institute for Health Research under its Programme Grants for Applied Research Programme [reference number RP-PG-0611-20005]. The views expressed are those of the author(s) and not necessarily those of the National Health Service, the National Institute for Health Research or the Department of Health.

Conflict of interests

None declared.

Key points

- Four, distinct viewpoints (family involvement, living in the present, pragmatic expectations and autonomy and individuality) on ahwat is important about end-of-life care for a person with dementia are identified.
- A consensus of participants' views is found for specific aspects of care: compassionate care, shared medical decision-making between family members and healthcare staff and information availability when making decisions.
- A 'one-size-fits-all' approach to end-of-life care policy is unlikely to be most appropriate due to the plurality of viewpoints identified.

References

Amador S, Goodman C, Robinson AL, Sampson EL. 2015. Development of a conceptual framework to assess quality in end of life care in dementia: contextual, structural, process and outcome variables. In European Association for Palliative Care (EAPC). Copenhagen, Denmark.

Ampe S, Sevenants A, Coppens E, *et al.* 2015. Study protocol for 'we DECide': implementation of advance care planning for nursing home residents with dementia. *J Adv Nurs* **71**: 1156–1168.
Baker R, Thompson C, Mannion R. 2006. Q methodology in health economics. *J Health Serv Res Policy* **11**: 38–45.
Brown SR. 1980. Political Subjectivity: Applications of Q Methodology in Political Science/Steven R. Brown; Foreword by William Stephenson. Yale University Press: New Haven.
Cramm J, Finkenflugel H, Kuijsten R, van Exel N. 2009. How employment support and social integration programmes are viewed by the intellectually disabled. *J Intellect Disabil Res* **53**: 512–520.
Crowther J, Wilson KCM, Horton S, Lloyd-Williams M. 2013. Compassion in healthcare – lessons from a qualitative study of the end of life care of people with dementia. *J R Soc Med* **106**: 492–497.
Davies N, Iliffe S. 2014. Response: compassion in healthcare – lessons from a qualitative study of the end-of-life care of people with dementia. *J R Soc Med* **107**: 134.
Davies N, Maio L, Rait G, Iliffe S. 2014a. Quality end-of-life care for dementia: what have family carers told us so far? A narrative synthesis. *Palliat Med* 1–12.
Davies N, Maio L, van Riet Paap J, *et al.* 2014b. Quality palliative care for cancer and dementia in five European countries: some common challenges. *Aging Ment Health* **18**: 400–410.
Dening KH, Jones L, Sampson EL. 2013. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med* **27**: 409–417.
Department of Health. 2008. End of life care strategy. Promoting high quality care for all adults at the end of life. London.
Department of Health. 2012. Compassion in practice. Nursing, midwifery and care staff. Our vision and strategy. Leeds.
Dickinson C, Bamford C, Exley C, *et al.* 2013. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *Int Psychogeriatr* **25**: 2011–2021.
Forrest J. 2010. Using Q methodology to assess chronic pain in elderly cognitively intact and Alzheimer's patients. *Operant Subjectivity* **24**: 38–48.
Hendriks SA, Smalbrugge M, Hertogh CMPM, van der Steen JT. 2014. Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* **47**: 710–720.
Hennings J, Froggatt K, Keady J. 2010. Approaching the end of life and dying with dementia in care homes: the accounts of family carers. *Rev Clin Gerontol* **20**: 114–127.
Kellehear A. 2013. Compassionate communities: end-of-life care as everyone's responsibility. *QJM* **106**: 1071–1075.
Lawrence V, Samsi K, Murray J, Harari D, Banerjee S. 2011. Dying well with dementia: qualitative examination of end-of-life care. *Br J Psychiatry* **199**: 417–422.
Lee RP, Bamford C, Exley C, Robinson L. 2015. Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC Palliat Care* **14**: 32.
Livingston G, Pitfield C, Morris J, *et al.* 2012. Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *Int J Geriatr Psychiatry* **27**: 643–650.
Mason H, Baker R, Donaldson C. 2011. Understanding public preferences for prioritizing health care interventions in England: does the type of health gain matter? *J Health Serv Res Policy* **16**: 81–89.
Mitchell S, Morris J, Park P, Fries B. 2004. Terminal care for persons with advanced dementia in the nursing home and home care setting. *J Palliat Med* **7**: 808–816.
National Collaborating Centre for Mental Health. 2007. Dementia: The NICE/SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. National Clinical Practice Guideline No 42. British Psychological Society and Royal College of Psychiatrists: Leicester and London.
NCP. 2009. Clinical practice guidelines for quality palliative care (national consensus project). edn second.
NHS - End of Life Care Programme. 2010. Care towards the end of life for people with dementia. An online resource guide.
NICE. 2015. Care of dying adults in the last days of life. National Institute for Clinical Excellence, NICE guidelines [NG31]: London.
Nuffield Council on Bioethics. 2009. Dementia: Ethical Issues. Nuffield Council on Bioethics: London.
Raymond M, Warner A, Davies N, *et al.* 2014. Palliative care servcies for people with dementia: a synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia* **13**: 96–110.
Robinson L, Dickinson C, Bamford C, *et al.* 2013. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but …'. *Palliat Med* **27**: 401–408.
Robinson L, Dickinson C, Rousseau N, *et al.* 2012. A systematic review of the effectiveness of advance care planning in dementia. *Age Ageing* **41**: 263–269.
Robinson L, Hughes J, Daley S, *et al.* 2005. End-of-life care and dementia. *Rev Clin Gerontol* **15**: 135–148.
Sampson EL, Harrison-Dening K, Greenish W, *et al.* 2009. End of Life Care for People with Dementia. Marie Curie Cancer Care UK: London.
Schmolck P. 2002. PQ Method 2.11.
Thuné-Boyle ICV, Sampson EL, Jones L, *et al.* 2010. Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia* **9**: 259–284.
Treloar A, Crugel M, Adamis D. 2009. Palliative and end of life care of dementia at home is feasible and rewarding: results from the 'Hope for Home' study. *Dementia* **8**: 335–347.
van der Steen JT, Radbruch L, Hertogh CMPM, *et al.* 2014. 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* **28**: 197–209.
Watts S, Stenner P. 2012. Doing Q Methodological Research: Theory, Method & Interpretation. SAGE Publications: London.
Westbrook JL, McIntosh CJ, Sheldrick R, Surr C, Hare DJ. 2013. Validity of dementia care mapping on a neuro-rehabilitation ward: Q-methodology with staff and patients. *Disabil Rehabil* **35**: 1652–1659.
World Health Organization. 2011. Palliative care for older people: better practices Eds. , Hall S, Petkova H, Tsouros AD, Costantini M, Higginson IJ (eds.). World Health Organization, Regional Office for Europe: Copenhagen.

Supporting information

Additional supporting information may be found in the online version of this article at the publisher's web-site.

Table S1: Statements written for a carer participant whose mother has dementia

