

Family caregivers' conceptualisation of quality end of life care for people with dementia: A qualitative study

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ABSTRACT

Background: People with dementia have been described as the 'disadvantaged dying' with poor end-of-life care. Towards the end-of-life people with dementia cannot report on the care they receive. It is therefore important to talk to caregivers; however, few have explored the views about end-of-life care from the caregivers' perspective. The majority of research on family caregivers has focussed on the burden and psychological impact of caring for a relative with dementia.

Aim: This study aimed to explore the views of family caregivers about quality end-of-life care for people with dementia.

Design: Qualitative study using in-depth interviews and analysed using thematic analysis.

Setting/participants: Purposive sampling from a third sector organisation's caregiver network was used to recruit 47 caregivers in England (2012-2013), consisting of; 1) family caregivers of someone who had recently received a diagnosis of dementia, 2) family caregivers currently caring for someone with dementia, and 3) bereaved family caregivers.

Results: Three over-arching themes were derived from the interviewees' discourse, including: maintaining the person within; fostering respect and dignity; and showing compassion and kindness.

Conclusions: End-of-life care for people with dementia does not differ from care throughout the dementia trajectory. Throughout the findings there is an implicit underlying theme of conflict. Conflict between family caregivers and an increasingly systematised service of care and conflict between family caregivers and professionals. This study has in particular

demonstrated the importance of the psycho-social aspects of care, aligning with the holistic definition of palliative care.

What is already known about the topic?

- People with dementia do not always receive good quality end-of-life care
- Caregivers descriptions of what ‘good’ or ‘bad’ quality care is may vary and are often a personal opinion which may not be shared among all

What this paper adds?

- Caregivers are less concerned with medical aspects of care and more the psycho-social aspects of care
- Principles of dementia care translate well with the broad principles of palliative care

Implications for practice, theory, or policy

- This study raises important questions about dementia care guidelines. Should general dementia guidelines include end-of-life care? Or should there be separate guidelines from general dementia care specifically addressing end-of-life care for people with dementia?
- The findings of this paper add to the debate around when end-of-life care for someone with dementia begins, with caregivers potentially describing a broad period of time as end-of-life.

INTRODUCTION

Dementia is a progressive illness with as yet no known cure or disease modifying treatment, (1). Given the ageing of populations it is becoming an increasing public health problem worldwide (2) and the delivery of high quality end-of-life care is becoming a high priority for health and social care services (3-5).

Prognostication for a person with dementia is notoriously difficult with the trajectory often marked with unpredictable fluctuations in the health of individual (6, 7). For people with dementia treatment of common symptoms (like pain) is poor, and access to specialist palliative care is limited(8), prompting an increase of research in these fields (9). More broadly, both care of older people and end-of-life care have independently come under scrutiny in England with the Francis Report, and the Neuberger independent review of the Liverpool Care Pathway (LCP) a widely used end-of-life care pathway (4, 10). The Francis Report examined failings in the treatment of older people in a specific hospital in England. The Neuberger independent review was an examination of the LCP, which was perceived as being misused and abused, with patients experiencing uncomfortable deaths. Both reports were a response to criticism of care quality from families, demonstrating the policy impact of families' views and voices (11). Most of the care for people with dementia is provided by unpaid family caregivers (12), and the Alzheimer's Society insists that without family caregivers the formal care system for people with dementia would collapse(13).

Previous research of family caregivers has focussed on the burdensome and stressful nature of caring, especially earlier in the course of the dementia caregiving journey (14). However, a recent review demonstrated that, internationally, little research has explored family caregivers' views of end-of-life care for people with dementia (15). The review commented that 'good' quality end-of-life care for someone with dementia is difficult to conceptualise,

and there is limited evidence about quality of care at the end-of-life. Only eight studies were identified and few directly discussed ‘quality’ of care. The review concluded that a much more detailed exploration of caregiver’s views is needed. Although palliative care includes care for the family, this study aims to respond to the call of the previous review and focus on family caregivers views of quality of care for the person with dementia.

DESIGN AND METHODS

Design

Qualitative methods using in-depth interviews. This study adopted both a prospective approach with caregivers currently caring for someone with dementia and a retrospective approach with ex-caregivers to provide a clearer understanding of how the quality of end-of-life care could be conceptualised.

Sample and recruitment

Three distinct groups of family caregivers were recruited:

1. Family caregivers of people who had recently received a diagnosis of dementia,
2. Family caregivers currently caring for someone with dementia,
3. Former family caregivers.

The participants were purposively sampled from the records of a national dementia charity in England. The charity has developed a network of over 1000 carers who are willing to participate in research. The aim was to purposively sample participants to fit each of the three distinct groups of carers. Recruitment and interviews continued until no new information or themes were being established from the data (i.e. data saturation was reached) (16).

Inclusion and exclusion criteria

Broad inclusion criteria were adopted to allow for the sensitive nature of the subject and the anticipated low response rate. End-of-life care was not pre-defined to the participants.

Participants were informed this was a study of end-of-life care, asked to consider their eligibility and if they believed they were or recently had been caring for someone who they perceived to be either at end-of-life or receiving end-of-life care.

Carers were not eligible to participate if:

- Their relative had died within the last three months
- They themselves had cognitive impairment.

Procedure and analysis

Ethical approval was obtained from (blinded for review) Research Ethics Committee (3344/001). All participants were sent an invitation for expressions of interests to participate from an English national dementia charity via email in two rounds of recruitment in May 2012 and February 2013; interested individuals received a verbal explanation and a written information sheet, and were given the opportunity to ask any questions. Written informed consent was obtained from participants. The topic guide (see supplementary file) was developed from reviews of the literature (15, 17-19), piloted with a small number of participants and developed iteratively throughout the study.

Interviews were conducted face-to-face because of the sensitive nature of the topic, by an experienced male researcher (blinded for review), but telephone interviews were conducted if participants preferred. Interviews are appropriate to use when dealing with complex and sensitive phenomena such as end-of-life care,(20) with some suggesting that in-depth interviews may have a therapeutic benefit to participants.(21) All interviews were audio

recorded and field notes were written following the interviews. Participants were given a choice of being interviewed at their own home, at the University, or an alternative venue of their choosing.

Participants were contacted the following day to thank them once more for their participation and asked if they required any additional support following the sensitive discussions.

Thematic analysis methods were used to analyse the data with a multidisciplinary research team, including a psychologist, an anthropologist, and two general practitioners. Two researchers independently coded five transcripts and met on four occasions to discuss codes and decide on a coding strategy for the remainder of the interviews. The remainder of the interviews were coded by (blinded for review) and a random selection were reviewed by (blinded for review). Following coding two researchers met to discuss clustering of codes and emerging themes, and revised these iteratively. Finally, themes were discussed among all members of the research team and relationships among the themes were explored/discussed in several meetings.

FINDINGS

Participants

47 family carers were recruited, and 45 individual in-depth interviews ranging from 30-120 minutes were carried out (4 by telephone), plus one interview with two participants (see table 1 and 2). A variety of caregiver occupations were reported including: University lecturer, engineer, company secretary and retired; although ethnicity was not recorded, participants were predominantly white British.

Table 1 near here

Table 2 near here

Themes

We identified three over-arching themes from the interviewees discourse, including: maintaining the person within; respect and dignity; and compassion and kindness.

Maintaining the person within

As dementia started to ‘take away’ the person they once knew, carers discussed the importance of maintaining the person within. They wanted to ensure that their relative was still treated as a person (in the sense of not just an object or just being seen as having dementia), and also an individual (having their own characteristics and personality making them unique). This theme encompassed three subthemes: paying attention to the individual and their needs, personalising and tailoring care, and providing an element of ‘normality’.

Attention

The attentiveness of others was described as talking to the individual, making sure they had everything they needed, and getting to know the person:

“We saw a doctor who, I must admit, was absolutely fantastic with him. He was just, he was a fairly young guy, hugely respectful of him, just listened to him. I was like, ‘My

dad has dementia' and he's like, 'Okay, but I'll still talk to your dad and I'll talk to you.' And he was just brilliant." (Daughter, bereaved, 041, 11:24)

Later in the course of the dementia the attentiveness of others became more specific, for example, from patiently sitting with the person with dementia and hand feeding them, ensuring that they still talked to them about what they were doing whilst providing care:

"The good quality, the regulars would do - would perform, you know, in terms of how we moved her, like always this habit of, whenever you're going to do something, you say you're going to do it and then you do it. So it doesn't come as a surprise or a shock. [...]" (Husband, bereaved, 030, 14:22)

Although only a small number of the caregivers interviewed had a relative die in hospital, many had experience of end-of-life hospital care and lack of attentiveness was mostly mentioned about care received in a hospital setting:

"Well in hospital they taught him to be incontinent [...] well they never took him to the loo. So, you know, it was just waiting until he either peed or pooped and then clearing it up." (Wife, bereaved, 042, 9:14)

However, inattentiveness was not restricted to hospital care, as there were also examples of care home and home care workers not showing enough attention. At times this was blamed on the lack of continuity and staff turnover or shift working:

"[...] I cleaned his mouth. But I found sandwiches from the night before [pressed] into his cheek. And I got the manager up and I said, 'Look his mouth hasn't been looked at for days, something has been in his mouth all night.' [...], 'This is not okay, what's this about?' you know. 'Has anybody even looked at my dad overnight?'" (Daughter, bereaved, 062, 24:21)

Personalisation and tailoring to individual need

Many felt that their relative was seen as ‘someone with dementia’ rather than ‘someone’ and therefore professionals often adopted what appeared to be a ‘generic dementia approach’. This approach meant there was no tailored care for individuals. For example, all people with dementia had to drink with a sipping cup instead of a ‘normal’ cup:

“[...]But they [care home staff] didn’t realise, they’d got a template for how to deal with dementing people, you know, ‘Here we go, this is the template, this is the protocol, you know, all dementia sufferers can’t feed themselves, so we’ll feed them, you know.’ And, of course, it wasn’t right at all for mum.” (Daughter, bereaved, 060, 3:25)

However, in addition to the ‘generic dementia approach’ there was also a standard care approach which may be true to all patients regardless of diagnosis, with medication given at standard times and meals at a specific time. There was a reluctance to deviate from ‘protocol’ for what some believed to be convenience and others simply fear:

“I’ve had to troubleshoot again and again and again and again and again, is giving him medication (dopamine for symptoms related to Parkinson’s disease) when he needs it. They become very rigid. They have a clipboard and on it, it’s got his drug rota. And, of course, hospitals are like this. If they’ve got the drug rota and it says, 6 o’clock in the morning - because he’s so advanced with the Parkinson’s, sometimes he cannot last from one dose to the next without looking like he’s at death’s door. [...]So I’ve had to go along to see the chief nurse and I’ve said, ‘He’s desperate for medication (dopamine).’ He looks at his watch and he says, ‘Oh well it’s not 2 o’clock yet,’ or, ‘He’s not due his next dose until 6.30.’ And I want to say, ‘Fuck the next...’ You know, you look at the patient. Why are you being ruled by a clipboard? A clipboard is a tyranny.” (Wife, currently caring, 006, 36:15)

Positive examples of tailoring did emerge however, there were many examples of care homes in particular taking an interest in the person with dementia's past role or hobbies. Others took detailed notes of what food and drinks they provided them with and whether they liked it:

“They keep a very close record of what everybody's eaten and drunk. They then try and offer something different if they haven't eaten or drunk whatever it is.” (Wife, currently caring, 016 – 44:18)

A sense of 'normality'

Maintaining a sense of normality for as long as possible was deemed important by participants. In particular, when in a care home or at home they wanted their relative to do as much as possible as close to what they had been able to previously. Caregivers wanted them to have engagement and social interaction or to do something that they would have normally done, hence maintaining a sense of 'normality':

“[...] In the better care homes, they would have a corner, if you like, where - and it's not always possible, where they - where it was safe, where they would just put a load of towels or tea towels or whatever and say, 'Sarah, can you just do that for me love?' and some days she'd do them and some days she didn't. But she had a choice.”
(Husband and daughter, bereaved, 043, 063, 22:30)

As the dementia progressed, this 'normality' simplified into just 'fitting in' with normal family life and remaining part of the family unit:

“I would wheel her through to the kitchen and she would sit at the table and we'd have some nice calming music on, and she would watch me cook and then try things [...]”
(Husband, bereaved, 030, 14:18)

Respect and dignity

Caregivers were less concerned about dignity in the early stages of dementia, but more in the final stages.

Caregivers frequently mentioned incontinence when they spoke about dignity, often with negative examples and in many instances because of the behaviour of individual staff members, and not the system:

“[...] You press the bell, you want to go [toilet] then, you don’t want to go - ‘I’ll be along with you in a second, I’ll just finish with this person.’ No, they need to go, you can hang on a little bit but you can’t hang on for ten minutes, which is what they expect you to do. ‘Well you’ve got a pad on, use that.’ I’m sorry, but you may have a pad on, but you don’t want to[...]” (Daughter, bereaved, 026, 2:4)

And some participants described how their relatives had been left naked in hospital:

“[...] It was then the discharge suite. I walked in to pick him up and he was sat in a green gown, half naked. [...] His legs exposed. He was soaking wet, soiled himself and he had somebody else’s glasses on. You know he had no sheet or blanket or anything covering his dignity [...]” (Daughter, bereaved, 015, 46:42)

There were however many examples of how people with dementia had been treated with both the respect and dignity that caregivers felt they deserved. To participants dignity in part encompassed being gentle and caring with the person with dementia:

“[...] She was respected and treated with dignity. And they used to be very gentle with mum, knowing that she doesn’t speak and she was very - like she used to fear people touching her because she probably had fear of injections or something. But they used to make sure she was fine [...]” (Daughter, currently caring, 056, 7:26)

“They keep the respect of the people. I know that sounds probably silly. But, you know, he’s not just a bod [body], you know [...]” (Wife, currently caring, 018, 23:17)

Compassion and kindness

Qualities of caring, kindness and compassion were described by many carers as essential:

“You need to have compassion if you’re looking after somebody at the end stage.”
(Daughter, bereaved, 008, 34:29)

Much of the disappointment and anger with ‘poor’ care was directed at nurses. In particular, when highlighting ‘poor’ care in hospitals, illustrations were based on the role of the nurses and what participants saw as a ‘failure’ of their role:

“But the nursing standards were dreadful. And when she came out, having gone in able to walk and talk, she could no longer walk and talk.” (Husband, bereaved, 020, 10:8)

The description of ‘poor’ nursing care was described as ignoring the needs of patients whether these were the medical needs or simple needs such as the delivery of food, or simply the way in which they spoke to individuals:

“One of the nurses accused my father of being [trouble], you know, she was a - you know, if I ever see her again, I’ll take a baseball bat to her face, I tell you! That’s how strongly I feel about her. I will punch her lights out. [...]there was another chap in there [hospital ward] who was in his nineties and he was like dad, a wanderer [...] And this auxiliary nurse came, grabbed him by the shoulders and put him on the bed and said, ‘Will you fucking stop moving?’ And I just thought, and those were the words.” (Daughter, bereaved, 015, 46:45)

Despite being focused on nursing care, many commented upon medical professionals' attitudes and aspects of interaction with them:

"[...] And when he finally did get somebody [GP] to come and see him, he [GP] just looked at him at home and just said to me, 'Hopeless case.' [...]" (Wife, bereaved, 031, 26:8)

Participants perceived there to be many reasons as to why some professionals were not as caring as they thought they should be. Participants felt that professionals were under many different forms of pressure which impacted upon their care including time, and health and safety regulations, but also a change in their professional role from their 'traditional role':

"[...] It's just a real difficulty at the moment in the NHS, that nurses do not see their role as caring, they see it as some kind of paramedical role." (Wife, bereaved, 004, 33:35)

Some discussed how care in the community was also limited by time:

"[...] They'd [home care workers] be like booked for half an hour and they'd be here for about ten minutes. But they were on such a timetable, it was just a case of that was the way they were making their money" (Husband, bereaved, 034, 12:11)

Although many negative experiences were reported by a number of caregivers, they did also talk about occasions where they had experienced 'good' quality care which they attributed to caring and compassionate staff. They were seen as able to sympathise, and to show concern or consideration for the person with dementia:

"[hospital] Ward was probably one of the nicest because the nurses seemed to bother, they seemed to care, they seemed to, they were still just as rushed off their feet, they

still spent far too much time on their computers. But they seemed to be much more caring, much more gentle [...]” (Daughter, bereaved, 026, 2:12)

Caregivers spoke highly of professionals who were willing to stay longer after their shift had finished. Some professionals were described as sitting with and caring for the person through their final hours when it was apparent they were close to death:

“[...] And he came back from the hospital about seven in the evening and I was already there. And bless, the carer [care worker] who was with him, she was way over her shift and whatever, and she said, ‘No I’m going to sit and make sure, and cook, let’s get him some pud,’ because my dad liked pudding [...]” (Daughter, bereaved, 041, 11:48)

Participants appreciated the mixture of both a professional side and a human emotional side to the care workers:

“And they were really upset [when the person with dementia died]. You know what I mean, it’s weird really, in a weird way that as quite comforting that they were so, you know, [...] I think again was - you knew that they cared.” (Daughter, bereaved, 041, 11:67)

The factors of time, reluctance to stick to the rules in order to provide appropriate care (as perceived by the caregivers), allowing for flexibility within these and going the ‘extra mile’ in the care of the person with dementia, together with a good understanding of dementia, seemed to form the crux of a caring, kind and compassionate professional.

DISCUSSION

This study explores the family caregiver’s views and experiences of end-of-life care for people with dementia and the meanings of ‘quality’, considering maintaining the person within, fostering respect and dignity, and demonstrating compassion in care.

It could be argued that many of the findings in this paper are not specific dementia care, all who receive care should feel respected and treated with dignity and compassion. Similarly, it could also be argued that many of the findings in this paper are also not specific to end-of-life care and address much of the dementia trajectory. However, caregivers were discussing what they believed to be end-of-life care, suggesting that perceived end-of-life care may span a much greater period than the final 12 months of life as some suggest.(22) Many have commented on the applicability of palliative care early in the course of dementia, even from the point of diagnosis, however concerns have been raised about this leading to the potential of dementia care itself being relabelled as palliative care (23). The current study compliments the European Association for Palliative Care's definition of end-of-life care as an '*an extended period of one to two years*' (24). This study also lends support to recommendation 1.2 from the EAPC white paper defining optimal palliative care for people with dementia, regarding when palliative care applies; '*improving quality of life, maintaining function and maximising comfort, which are goals of palliative care, can be considered appropriate throughout the disease trajectory, with the emphasis on particular goals changing over time*' (1).

The findings discussed in this paper suggest that caregivers are not looking for intensive medical treatments and processes in order to judge the quality of care; instead they are searching for a holistic approach to care which is person centred and considers the interpersonal and social aspects of care. This stance from caregivers aligns with many definitions of palliative care (which includes end-of-life care) (24-26) and supports the notion that others have marked that palliative care compliments dementia care principles (12, 23). However, in a climate of high pressure and a demanding workload this appears difficult to deliver, particularly in acute care settings.

This paper has presented in addition to the answers of what families want from end-of-life care for the person with dementia, several other issues which need to be explored further. Throughout the findings there is an underlying theme of conflict. Conflict between family caregivers and an increasingly systematised service of care and conflict between family caregivers and professionals namely what appears to be nursing staff. The idea of conflict appears to be in contrast to the cancer literature. The cancer literature discusses conflict in terms of battles, fights and other military metaphors about overcoming the disease itself (27).

A particular aspect of conflict demonstrated in the findings focusses on the disappointment with nursing staff. This supports findings from earlier work (28, 29), and echoing the findings of Tadd and colleagues that the acute hospital may not be the right place for older people (30). There could be many reasons as to why nurses were seen to take the majority of the criticism within this study from caregivers, however these reasons are likely to be complex. The role of the nurse is suggested to have compassion at its core (31). Therefore when this is seen as sometimes lacking by caregivers and their expectations of care are not met these unmet expectations and lack of perceived compassion may impact upon their views and opinions of their experiences. A study of professional boundaries found that one of the key distinctions between nurses and physicians was time spent with patients (32), with nurses spending more time. In this sense nurses are seen as ‘frontline’ and often the ‘face’ of the NHS, therefore the ones that are likely to be judged by caregivers.

Implications for research, policy and clinical practice

This paper has implications for how we move forward with policy and guidelines, offering many questions which must be asked and considered. Does care for people with dementia, need dementia guidelines which incorporate palliative and end-of-life care, or do we need separate guidelines specifically for dementia and end-of-life care? The risk of the

combination is that important aspects of end-of-life care may be overshadowed in general dementia guidelines, however separate guidelines have the potential to miss the importance of the themes discussed in this paper which run through the course of dementia care. Despite these concerns the authors welcome the publication of the white paper defining optimal palliative care for people with dementia (1).

Although this study does not explore directly the applicability of palliative care earlier in the course of the dementia, the lack of end-of-life specific issues creates uncertainty about when caregivers' believe end-of-life and hence palliative care begins in the trajectory. Further work with family caregivers should explore this and inform this debate. Finally, further work needs to consider the conflict between families and the nursing role, unpicking the issues raised in this study to understand this aspect of conflict.

Strengths and Limitations

A strength of this study is the number of participants recruited, with 46 interviews this is large for a qualitative study.

As participants were selected from a caregivers' network which is responsible for sharing experiences and lobbying, it is possible that many of the participants would represent 'extreme' cases, either 'very good' or 'very poor' experiences. Previous work provides conflicting evidence for this (33, 34) and we would argue this study demonstrates a mixture of both positive and negative experiences.

A particular strength of this study was the team approach to the analysis and thorough methods to enhance the rigour of the analysis, including independent coding of transcripts initially and searching for deviant and negative cases (35, 36).

Participants were recruited for this study through email, this may have excluded older carers who could be less likely to have computer access. However, figures suggest that 70% of those aged 65 and over use the internet on a daily basis (37).

A further potential sample limitation is the possibility of participant recall and attention bias. This may be particularly true of the retrospective sample, although due to the emotional nature of the situation participants might be expected to have better recall (38, 39).

Conclusions

This study highlights the importance of psycho-social care for people with dementia at the end-of-life, reporting little on clinical and medical aspects of care. This psycho-social view fits with definitions of palliative care (1, 24, 25).

The views of caregivers in this study suggest that care at the end-of-life need not be complex. End-of-life care for dementia is not particularly different from care of the person with dementia throughout the trajectory and encompasses many of the aspects of a palliative approach regardless of condition.

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Disclaimer

The views expressed are those of the authors and not necessarily those of the European Commission.

Competing interests

None declared.

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