

The Experience of Living with and Caring for Someone with Dementia at the End of their Life

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Background

There are over 800,000 people in the UK with dementia¹ which is expected to rise to over 1 million by 2050². With no known disease modifying treatment end of life care is rapidly becoming one of the major priorities for dementia care.

There are over 670,000 family carers of people with dementia in the UK³. Family carers often provide the majority of informal care for someone with dementia at home, however this becomes less possible as people move closer to the end of life⁴. Little is known about the experiences of family carers for people with dementia at the end of life and their views on quality of care^{5,6}.

Aim

This study explored what are the 'good' and 'bad' features of good quality end of life care for people with dementia, from the perspective of family caregivers.

Method

Design

Qualitative methodology using in-depth interviews

Participants

- Family carers of people who are currently dying with dementia
- Bereaved family carers of someone with dementia

Procedure

- Participants were purposively sampled from a national charity which has a register of carers.
- A topic guide was developed from literature reviews of the field, was tested and changed iteratively throughout the interviewing process.
- Face to face or telephone interviews were conducted, according to participant preference.
- Interviews were transcribed verbatim and are being analysed using thematic analysis methods

Results

Participants

46 interviews (42 face to face and 4 telephone interviews) were completed across England in 2012 and 2013, with 47 family carers of people with dementia. 32 were bereaved carers and 15 were carers currently caring for someone dying with dementia. The majority were adult children (29) and the remainder were spouses (17) and a close friend (1).

Themes

Discussion of good quality end of life care highlighted several key issues which carers felt strongly about including when they thought end of life care began and how this was associated with palliative care. For this poster what family carers thought were the key aspects of 'good' quality end of life care for the person with dementia are highlighted below including: Attention; personalisation and tailoring, maintaining a sense of normality; respect and dignity; and basic care.

Attention

Attention and time received from professionals was crucial. This initially began as chatting to the individual, making sure they had everything they needed, advancing to more detailed aspects of attention, for example sitting with them and feeding them being patient with this, ensuring that despite not being able to hold a conversation they still talked to them about what they were doing whilst doing it (i.e. whilst changing them), ensuring their mouth was moist and swabbed.

"[...] they were really, really doing everything they could to try and ease things for mum and for me. I think they were, that's right, they were swabbing her mouth with water as well because she needed, you know, fluid." (038 – 13:25)
"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" (042 – 9:14)

Personalisation and tailoring

'The dementia approach' was what many carers perceived professionals to take, which is rather ironic as really there is no one approach which fits everyone who has dementia when caring for them. 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 approach; 'the dementia approach' when caring for them. For example all people with dementia liked to be shown affection.

"[...]she came bustling in [care assistant] and she went right up to my mother and sort of did this to her, you know, how you do. And she said, 'Oh hello K, I love to see your lovely smiley face.' And you thought, 'Any moment now you're going to get hit over the head woman,' you could see it, you could see mum bridle, because as I said, there was this Edwardian business about, 'Don't come near me' [...]" (060 -3:18)

Maintaining a sense of 'normality'

An element of 'normality' was important. 'Normality' in the earlier stages entailed enabling the person with dementia to do as much as possible as before, remaining socially active. For example social interaction through gardening or 'DIY'. With the progression of dementia this eventually became simply 'fitting in' with family life and being able to remain at home with the family.

"And in the first week they'd taken him out - she rang me up and said, 'Am I allowed to take your dad out?' 'Of course, where are you going?' 'We're going to the pub.' I said, 'Well he's not a big drinker, but if he does drink, it will be mild.' But, you know, that was normal." (005 – 32:24)
"We wanted her to still be part of the family and the children to come in." (044 – 8:28)

Respect and dignity

All families were concerned with the level of dignity that their relative had or perceived that they had. This appeared less concerning in the early stages of dementia than in the final stages when the person was no longer able to communicate and preserve their own dignity alone, but relied on the actions of others to ensure their dignity was maintained. Families in particular spoke about incontinence and personal care when they spoke about dignity.

"[...] But I said [my husband] wouldn't know what a toilet was, he has to be taken to the toilet, he doesn't know the difference between a toilet, a bath, a sink, he doesn't know what a toilet is'. [...] And she said [nurse], 'Oh,' she said, 'Not to worry,' she said, 'If he pees on the floor, that's okay'" (013 - 43:11)
"[...]they stood him in front of the sink, with a wet flannel, up his front, down his back. Again it was totally humiliating [...]" (004 – 33:20)

Basic Care

Many of the carers talked about simple elements of care such as pain management, ensuring the person was dressed in their own clothes and not those of others, having caring and compassionate staff who were familiar to the person with dementia. Many did not see that the care was that different to that of any one else with a terminal illness.

"[...] And when he finally did get somebody to come and see him, he just looked at him at home and just said to me, 'Hopeless case.' [...]" (031 – 26:8)
"She'd have other people's clothes on, you know, despite the fact that we'd carefully labelled everything." (050, 16:11)
"I wanted her to be – well I wanted her to be comfortable and not suffering pain, that's the thing I wanted most [...]" (044, 8:11)

Conclusion

- GPs need to have a more prominent role in palliative care for people with dementia
- Family caregivers need more support. People with dementia and their carer need to be thought of together as a unit, a dyad.
- ACP is important for all people with dementia ACP should always be tailored to the individual person and family.

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