

A UK Qualitative Study of Life of Living and Dying With Dementia in the Last Year of Life

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Abstract

It is difficult to establish and care at the end of life for people with dementia from the perspective of bereaved family carers of people with dementia. In this study, 10 bereaved family carers of people with dementia were interviewed. Issues with the unpredictability of living and dying were identified, and carers were often referred for specialist palliative care. The need for high quality end of life care of people with dementia is identified.

environment (family home, care home, hospital). Exclusion criteria included Paid/ formal carers; Under 18 years of age; death occurred more than five years previously. Family carers were invited to contact the first author if they were interested in participating in the study and were sent an information pack which included an information sheet and reply letter to invite the first author to contact them. Following written consent being obtained, interviews were conducted with participants and digitally recorded and transcribed verbatim. Interviews lasted between 30 minutes and 80 minutes. Interviews were conducted face to face usually at the participants home, with a small

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|----------------------|-----------------------|
| 69 – 96 years | 81.5 years |
| Time Spent Caring | Mean Time Caring |
| 18 months – 20 years | 5.1 years |
| Time Since Death | Mean Time Since Death |
| 3 months - 5 years | 1.7 years |

Table 1: Information Regarding Participants.

The mean length of time from formal diagnosis to death was 4.5 years, however, most participants reported cognitive problems for some time prior to diagnosis. Four participants were family carers for people who had a dual diagnosis of cancer and dementia. Of these, three experienced specialist palliative care services: one in a day hospice: one hospital based and one a community based specialist

palliative care service. As a result of constant comparison of individual transcripts, twenty three categories emerged from the data. Over a period of time data was reduced further and the following key themes began to emerge: communication; family carers as experts; the hard work of caring; and living and dying with dementia in the face of uncertainty. An example of an interview coding is included in Table 2.

| Participant | Initial coding | Text | Memos |
|-----------------|---|--|---|
| Family Carer 36 | Control, collaboration, attempts to include as well as being/feeling excluded, anger towards formal carers, vulnerability of person with dementia | "and then like when they wanted to turn her and change her position, they were very good and she had mouth care and they asked if I wanted to do it and things like that, she really didn't need a lot of care towards the end, mum she was just never, she was just so understanding, she was amazing, didn't really need very much so when we were asked to leave the room, we both went out the room, Dad used to get very angry about that "why you putting me out?" and things like that and so forth"..... | Person with dementia so dependent upon others now for all activities of daily living interpreted by daughter as undemanding, is this measured by communication and requesting things verbally? Appeared to demand high levels of input from formal carers, could be interpreted as being demanding by them?? Demanding upon resources?? Daughter feeling excluded from care, explanations for this action from formal carers could have reduced anger felt at exclusion, similar to other scripts, family carer 14 |

researcher was initially aware of the importance of communication with the person with dementia

uncertainly experienced her, very, very poorly, still very poorly, the

said, (family carer 30). Occasionally a deterioration was reported and

interpreted to mean the person with dementia was close to death. There

horrible the way me dad died, absolutely horrible...it was dreadful...
if he'd have been in a side room... had a little bit of dign&MI...

hard work and the caring tasks required on a regular basis to support daily living and the emotional hard work related to burden, stress, anxiety and guilt. The constant “battles” family carers described when trying to negotiate the world of professional care was a drain on their emotional resources and such situations impacted on family carers

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