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Family Perceptions about 'Good' and 'Poor' Quality End of Life Care for

People with Dementia

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Background: In England there have been many reports of 'poor' care received at the end of life. Concerns have been highlighted in some areas of England about the care delivered to older people and particularly people with dementia. Much of this has been revealed in reports from families.

Aim: To explore the meanings of 'good' and 'poor' quality end of life care for people with dementia, from the perspective of family carers.

Method: 46 in-depth interviews with family carers of people recently diagnosed with dementia, or who were currently caring for someone dying with dementia, or who were bereaved. Interviews were analysed using thematic analysis methods.

Results: Participants highlighted the central role they played as carers. This role was sometimes relied upon too much by professionals. This led to an over reliance on them as carers. They often felt unsupported in three domains of caring: 1) care management, 2) physical caring, and 3) managing the emotional and psychological demands of caring.

Participants described their frustration at being left to coordinate the care for the person with dementia. They felt at times that they were the 'case manager' for the person with dementia, or 'chief executive' of the individual's life and affairs, losing their identity as a 'relative'.

Participants did not talk in terms of 'palliative care'. They spoke about more basic aspects of care at the end of life. Care for the person with dementia was thought to be lacking in many basic areas, in particular attention and compassion from nursing staff. Participants associated the decline in this with a change in the nursing role to one that is task focussed and 'paperwork heavy'.

Conclusion: Carers do not focus on the technical medical aspects of end of life care, but are more concerned with the interpersonal aspects of care. Carers of people with dementia

need to be recognised as advocates for their relatives as well as being in need of support themselves.