

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

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Abstract

Background: Dementia is a life limiting illness, but the trajectory of dying can be difficult to establish and care at end of life can be variable.

Methods: This UK study was carried out to explore the end of life care experiences of people with dementia from the perspective of their family carers. In depth interviews were conducted with forty bereaved family carers of people with dementia.

Results: Forty family carers (male n=9, female n=31) age range: 18-86 years were interviewed. Issues with poor communication were common. The hard work of caring and issues regarding unpredictability of living and dying with dementia were also commonplace within the study. Only three patients were referred for specialist palliative care support at the end of life and all of whom had a dual diagnosis of dementia and cancer.

Conclusion: This large qualitative study has identified that there are several gaps in the end of life care of people with dementia and frequently there is poor communication during the last year of life. The need for high quality integrated care for people dying with dementia with appropriate support during the last year of life is identified.

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Biography

Jacqueline Crowther is currently working for Department of Primary Care and Mental Health, University of Liverpool, Brownlow Hill, Liverpool, UK. Has attended

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