

A model of activity patterns for people with dementia: family carers' perspectives

Pat Chung¹, Caroline Ellis-Hill², Peter Coleman²

¹Canterbury Christ Church University, Kent, United Kingdom, ²Southampton University, Southampton, United Kingdom

Introduction/objectives

Participation in meaningful activity is essential to the well-being of people with dementia (Perrin et al, 2008). UK government policy encourages practitioners to work in partnership with family carers in the delivery of intervention programmes (DH, 2005; NICE, 2006). Occupational therapists play a key role in supporting people with dementia by suggesting home-based activity programmes undertaken by their carers (DH, 2001). Knowledge about carers' involvement in the continuing activity needs of individuals at all stages of dementia is fragmented. This study explored carers' own perceptions of their engagement with their relatives in everyday activities at home.

Method

Following research governance and ethical approval, 30 in-depth interviews (i.e. initial and follow-up) were carried out with 15 resident-carers (4 male, 11 female; aged 50's-80's years) of people with dementia who were recruited via local community teams. Then five focus groups were conducted with 21 participants (8 male, 13 female; aged 40's- 90's years (14 resident-carers and 7 ex-carers) through carers support groups. Interviews and focus groups explored the experiences of involving the cared-for in daily activity, including carers' strategies, feelings and reflections. Interviews were tape-recorded, transcribed and analysed using grounded theory (Strauss and Corbin, 1998).

Results

Themes were identified which formed a model consisting of five activity patterns (i.e. usual, recognisable, illogical, irresponsible and dispossessed). The model illustrated the complexity and dynamic nature of family carers' decision-making over time. It provided deeper insight in the understanding of the negotiation processes in which carers made activity-related decisions and developed strategies; and how such process challenged carers' own sense of self.

Conclusion/contribution to practice

The model offers a new approach for professionals to use as a basis for everyday activity-based intervention which takes the carer's perspective into account. This will ensure that any intervention is more likely to be carried out by family members and that professionals can support family members as well as the person with dementia more effectively. Further research will focus on developing a toolkit to enable practitioners to recognise the complexities, uncertainties and conflicting values which confront carers in their activity-related decision-making and so aid partnership working.