

Quality of life in family carers of people with dementia

C-DEMQOL STUDY

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Caring for somebody with dementia

- Dementia takes places in the context of a relationship, most commonly spousal or parent/child
- In 2012, there were 670,000 family carers of people with dementia in the UK (Alzheimer's Society, 2012), whose caring contribution is estimated to be 44% of the overall cost of dementia in the UK, currently £26.3 billion (Prince et al., 2014).
- The outcomes of people with dementia and their carers, whilst different, are inherently linked. Family carers are a vital determinant of quality of life and positive outcomes for people with dementia.

Our research

- The key aim of the study is to develop C-DEMQOL, a questionnaire to measure Quality of Life (QOL) in family carers of people with dementia
- Seven stages over a 30 month period, starting in October 2015.

What we have done so far

- We carried out individual interviews and focus groups with 38 family carers and 14 staff
- 12 themes were identified from the analysis which were to develop the items (questions) in the new questionnaire
- First version of questionnaire was tested with 25 carers in 2016
- Second version of the questionnaire was tested with 120 carers in late 2016/early 2017

Person with dementia

- **Relationship with the person with dementia**

'I think he's more like my child than my Dad now. He's like a big toddler.'

- **Change in the person with dementia**

'He will just explode, and he will shout and scream and his voice will go up and ...everything's our (family carer and daughter) fault.'

- **Demands of caregiving**

Carer appraisal

- **Personal freedom**

Yes, well, you know, coming to terms with the situation I'm in where I'm almost a prisoner, really.'

- **Acceptance of the caring role**

'You know, I say to him, "You'd have done it for me" and he would...I just think of it as, of course I would.'

- **Finding meaning**

- **Carer health**

- **Expectations of the Future**

External world

- **Evaluation of support**

We're trying to get some money from Social Services (to fund domiciliary support) and we're having a... battle.'

- **Weight of responsibility**

'It's the sense of responsibility for his life.' ‘

- **Family and Social networks**

'The things that probably keep me going are external, our friends. We chatter on the phone and by messenger, email and whatever, texts.'

- **Role conflict**

Involving carers in the study in the Lived Experience Advisory Panel

- Involvement was an integral part of the grant proposal
- A member with lived experience of care-giving is attached to the research team throughout the study.
- 4 Carers recruited to the Lived Experience Advisory Panel
- Jean Southey to co-ordinate meetings with researchers
- The LEAP to meet regularly at key times during the research process.
- “Involvement Log” to show carer impact on the study.

Experience of Involvement in the LEAP group and taking part

- Ellen Jones, Jay Kramer and Julia Fountain.....

Next steps

- We are starting to test the final version of the new questionnaire and we are currently looking for family carers
- New questionnaire will be freely available from March 2018
- Intended to be widely used



If you are interested in getting involved in the research please
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