

# Quality of life in carers of people with dementia (C-DEMQOL Study)

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## Background & aims of the study

The principal aim is to develop a condition-specific questionnaire to measure the Quality of Life (QOL) of family carers of people with dementia. The first stage of the study involved the completion of a qualitative study in order to identify the factors influencing QOL in family carers of people with dementia. We have also carried out two systematic reviews; one into the factors associated with QOL of carers of people with dementia, and one into instruments measuring QOL in carers of people with neurodegenerative diseases.

## What did we do?

41 individual interviews with 32 carer participants and 9 staff participants. Two focus groups; one with carers (n=6) and one with staff (n=5). The qualitative study utilised ground theory techniques and was underpinned by a collaborative approach with a study-specific Lived Experience Advisory (LEAP) group.

## Carer demographics

Characteristic	Range	Mean
Age	45.9 – 84.8 years	66.05 years
	Type	Number (%)
Gender	Female	24 (64.9)
	Male	13 (35.1)
Ethnicity	White British	32 (86.5)
	White Irish	1 (2.7)
	Indian	3 (8.1)
	Persian	1 (2.7)
Relationship to the person with dementia	Spouse/partner	21 (56.8)
	Son/Daughter	14 (37.8)
	Daughter-in-law	2 (5.4)
Resident/ Non-resident	Co-resident	24 (64.9)
	Non-resident	13 (35.1)
Living situation	Own home	29 (78.4)
	Care home	8 (21.6)

## What did we find?

From the analysis, we identified three over-arching themes; and 12 sub-themes. Carer assessment of their relationship with the person with dementia; and their appraisal of the demands and support provided were critical factors in their assessment of their own QOL.

### Theme one: Person with dementia

- Relationship with the person with dementia - change or maintenance in the nature of the relationship, change or reversal in roles. Loss of recognition/ reciprocity. Pre-existing relationship very significant  
*'I think he's more like my child than my Dad now. He's like a big toddler.'*
- Change in the person with dementia – change in the personality of the person with dementia, and impact of some of the symptoms of dementia on the person and carer  
*'You live with someone for 33 years and suddenly this is not the person that you loved.'*
- Demands of care giving - delivery of care to/and supervision of the person with dementia  
*'He's only at home because of us... we are this huge super structure holding it all up.'*

### Theme two: Carer appraisal

- Personal freedom - degree of restriction upon being able to undertake own preferred activities; loss of freedom and spontaneity  
*'Our life is hugely ruled by Dad and his timetable.'*
- Carer expectations - degree of willingness to provide care  
*'I just think of it as, of course I would.'*
- Finding meaning - pride in achievements of caring for the person with dementia, making the person as 'happy' or their QOL being as good as possible  
*'I feel that actually she's got a good quality of life now.'*
- Carer health - perceived impact of care-giving on the health of carer  
*'My fear, is my health.'*
- Expectations of the Future – degree of concern about the future  
*'That's why I just dread the next thing that's going to happen.'*
- Role conflict – trying to meet differing demands  
*'Yes, it's the pulls in all the different directions.'*

### Theme three: External world

- Evaluation of support – assessment of support (family or service) being given or offered and having choice in the type of help received  
*'We're trying to get some help from Social Services and we're having a battle.'*
- Weight of responsibility - feeling overwhelmed by the amount of responsibility/feeling solely responsible  
*'I put it down to the fact that I have been left with it all.'*
- Family and Social networks – extent to which there is social contact, help from friends or involvement of wider family members, value of contact with others  
*'Without the family support I don't know where we would be.'*

## Conclusions and next steps

These findings make a novel contribution to existing knowledge and demonstrate that the QOL of carers of people with dementia includes domains which are not routinely considered in generic assessment of QOL. Development and field testing of the new measure will take place with 445 carers across Sussex and North London.

### For more information

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