



Phase 1 – Interviews with carers

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Background

- There are numerous quality of life questionnaires with many used in the assessment of dementia carers
- Recently the Medical Research Council stated:

*Tools for
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Tools for assessing quality of life of people with cognitive impairment and other chronic conditions have been developed, but it appears that these do not adequately capture the full burden of being a carer, nor of the health consequences of caring. The validity and reliability of these instruments is also still very uncertain.

Aim

- To develop a new reliable and valid measure for assessing the Quality of Life (QoL) of carers of people with dementia
- Needs-led from the experiences of carers
- Short enough to be used
 - in routine health and social care, and third sector practice
 - in research
 - with the potential to be used for valuation

Workstream 1

Phase 1
Item generation

Phase 2
Item refinement

Phase 3
Psychometric
evaluation

Workstream 2

Study 1
Health state
valuation
comparison

Study 2
Carer QoL / EQ5D
calibration

Study 3
Direct valuation of
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Phase 1 - Method

- Semi-structured interviews (30 – 180 mins)
- Needs-led approach to analysis
 - A move away from classical Health-Related Quality of Life
 - Symptoms and functioning
 - Derived from ‘needs theory’
 - Assesses extent to which a circumstance or condition restricts the fulfilment of the needs of the individual
 - Socratic questioning
 - Research team analysis

Participants

N = 42

Age = 62 (31-83)

Ethnicity	Kinship	Gender	N
White British – rural	Spouse	Female	4
		Male	5
	Adult-child	Female	2
		Male	2
White British – urban	Spouse	Female	5
		Male	5
	Adult-child	Female	7
		Male	2
South Asian	Any relationship	Female	2
		Male	0
Black	Any relationship	Female	3
		Male	1
Any ethnicity	Daughter-in-law		1
	Young carer (<35 years)		1
Any characteristics			2

Phase 1 – Findings

- Multiple iterations of needs-based frameworks
- 3 super-ordinate needs
 - Needs relating to self (carer)
 - Needs relating to the person with dementia
 - Needs relating to managing care
- 12 needs and themes within those needs
- 100 sub-themes within the themes (where most items will be generated)

Super-ordinate theme 1

Needs relating to self (carer)

- Need for freedom to be something other than a carer
 - I am able to talk to people about something other than dementia and care
- Need for an outlet
 - I can tell people how I feel without being judged
- Need to maintain values and integrity
 - I do not like asking for help
- Need for certainty
 - I do not know how or when things will get worse
- Need to feel connected
 - I feel like people still care about me
- Need to maintain physical well-being
 - I am able to get enough sleep

Super-ordinate theme 2

Needs relating to the person with dementia

- Need to protect the person with dementia
 - It's hard to know when to help them and when to let them do things for themselves
- Need to feel close to the person with dementia
 - We have to find new activities to share together
- Need to fulfil duty to the person with dementia
 - I am able to provide the person I care for with good experiences

Super-ordinate theme 3

Needs relating to managing care

- Need to have professional reassurance and support
 - It's important that we are supported by caring medical professionals
- Need to feel in control
 - I need to be listened to and heard by services
- Need to 'get it right'
 - I have to deal with a lot of other peoples opinions about what I should and shouldn't do

Example extracts with sub-themes

Example extract 1

There's just so much going on, it's, I do a lot of thinking in the car, on the way home usually, yes, because I'm going back to it, so I'm constantly churning it over, and I crave time by myself. Sometimes I just go, I'm going upstairs and I just, but then he just keeps appearing, this is a new thing, appearing, wandering, it's like I suppose he's trying to anchor himself, so he follows me around, sometimes I'll say "leave me alone, go downstairs," I feel awful. I constantly feel awful, just for wanting normal things.

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I feel guilty about...

Example extract 2

...there's always something I should be doing, that you know, I need to do, or, just ruminating about stuff, and trying to sort out problems and appointments, a lot of that, you know, you try to balance the, you know, I do 30 hours at work, but I also have to take Michael to the dentist, and also have a meeting with social services and also I have to go to the GP, and my son needs me too...

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I have other responsibilities outside of providing care

Next steps

- Disseminate qualitative findings
- Develop and refine an item pool
- Distribute new measure in phase 3
- Refine and complete assessment tool

Outcomes

- Qualitative understanding of the way that caring impacts the needs of carers
- A new and robust measure for use in the assessment of carers

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