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 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 of someone with these conditions, nor of the health consequences of caring. The validity and reliability of these instruments is also still very uncertain.*
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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 Carer QoL items

DECODE
Dementia Carers Instrument Development
Workstream 1

Phase 1
Item generation

Phase 2
Item refinement

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Psychometric evaluation

Workstream 2

Study 1
Health state valuation comparison

Study 2
Carer QoL / EQ5D calibration

Study 3
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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

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N = 42

Age = 62 (31-83)
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
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 need to relax and switch off
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I need to relax and switch off
I need time to myself
I am always having to cope with something new
I feel guilty about...
...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...
Example extract 2

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I have a long list of things that I never get around to doing

I spend a lot of time sorting out services

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
Thank you to all participants and project partners

All 42 carers who gave up their time to participate

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All at Bradford District Care Trust

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