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Title **Measurement of Health-Related Quality of Life for People with Dementia: Development of a New Instrument (DEMQOL) and an Evaluation of Current Methodology**

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Aim

To develop and validate a psychometrically rigorous measure of health-related quality of life (HRQL) for people with dementia. The measure was intended to be:

- Suitable for use in the UK
- Available in both self- and proxy-report versions for people with dementia and their carers
- Appropriate for use in mild/moderate and severe dementia.

Conclusions and results

The conceptual framework included 5 domains: daily activities and looking after yourself, health and well being, cognitive functioning, social relationships, and self-concept. The preliminary field test versions of DEMQOL and DEMQOL-Proxy contained 73 questions representing the 5 domains and a global question about overall quality of life. Item reduction analyses resulted in a 28-item DEMQOL and 31-item DEMQOL-Proxy. Rigorous evaluation in 2-stage field testing in 241 people with dementia and 225 carers demonstrated that in psychometric terms: i) DEMQOL is comparable to the best available dementia-specific HRQL measures in mild-moderate dementia, but inappropriate for use in severe dementia (MMSE <10); and ii) DEMQOL-Proxy is comparable to the best available proxy measures in mild/moderate dementia and shows promise in severe dementia. Furthermore, the DEMQOL system has been validated in the UK in a large sample of people with dementia and their carers, and it provides separate measures for self and proxy report, which allows outcomes to be assessed across the wide range of severity and care in dementia.

Recommendations

The 28-item DEMQOL and 31-item DEMQOL-Proxy provide a robust method to evaluate HRQL in dementia. The new measures show comparable psychometric properties to the best available dementia-specific measures, provide both self- and proxy-report versions for people with dementia and their carers, are appropriate for use in mild/moderate dementia (MMSE ≥10), and are suitable for use in the UK. DEMQOL-Proxy also shows promise in severe dementia. As DEMQOL and DEMQOL-Proxy give different but complementary perspectives on quality of life in dementia, we recommend using both measures together. In severe dementia, only DEMQOL-Proxy should be used.

Methods

We used gold standard psychometric techniques to develop DEMQOL and DEMQOL-Proxy. First, we generated a conceptual framework from a review of the literature, qualitative interviews with people with dementia and their carers, expert opinion, and team discussion. We drafted and piloted items for each component of the conceptual framework to produce questionnaires for people with dementia (DEMQOL) and carers (DEMQOL-Proxy). We undertook 2-stage field-testing of both measures in large samples of people with dementia representing a range of severity and care arrangements. In the first field test (n=130 with dementia, n=126 carers), we eliminated items with poor psychometric performance separately for DEMQOL and DEMQOL-Proxy to produce two shorter, more scientifically robust, instruments. In the second field test, we evaluated the item-reduced questionnaires along with other validating measures (n=101 with dementia, n=99 carers) to assess acceptability, reliability, and validity.

Further research/reviews required

Further research with the DEMQOL system is needed to:

- Confirm these findings in an independent sample
- Evaluate responsiveness
- Investigate the feasibility of use in specific subgroups and in economic evaluation
- Develop population norms. Additional research is needed to address the psychometric challenges of self-report in dementia and validating new dementia-specific HRQL measures.

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