Measurement of health-related quality of life for people with dementia

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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Executive summary

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Executive summary

Background

Dementia is one of the most common and serious disorders in later life. It causes irreversible decline in global intellectual and physical functioning, and has a significant personal, social, health and economic impact on people with dementia, their family carers, and health and social services. Although measures of cognitive, functional and behavioural outcomes are widely used to evaluate interventions for dementia, the challenge of measuring broader outcomes such as health-related quality of life (HRQoL) has only recently begun to be addressed. This presents challenges about how to assess the subjective perceptions and experiences of the person with dementia in a reliable and valid way. This report describes the development of a new measure (DEMQOL) to evaluate HRQoL in people with dementia. The new measure is designed to address limitations and/or gaps that were identified in existing dementia-specific measures.

Objectives

The purpose of this study was to develop and validate a psychometrically rigorous measure of HRQoL for people with dementia. The measure was intended to be: (1) suitable for use in the UK; (2) available in self- and proxy-report versions for people with dementia and their carers, respectively; and (3) appropriate for use in mild/moderate and severe dementia. The aim was to keep the perspective of the person with dementia central in all stages of questionnaire development and evaluation.

Methods

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

Results

The conceptual framework included five 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 five domains and a global question about overall quality of life. Item reduction analyses resulted in a 28-item DEMQOL and a 31-item DEMQOL-Proxy.

Rigorous evaluation in two-stage field testing with 241 people with dementia and 225 carers demonstrated that in psychometric terms: (1) DEMQOL is comparable to the best available dementia-specific HRQoL measures in mild to moderate dementia, but is not appropriate for use in severe dementia [Mini Mental State Examination (MMSE) <10]; and (2) DEMQOL-Proxy is comparable to the best available proxy measure in mild to moderate dementia, and shows promise in severe dementia. In addition, 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-report and proxy report, which allows outcomes assessment across a wide range of severity in dementia.

Conclusions

The 28-item DEMQOL and 31-item DEMQOL-Proxy provide a method for evaluating HRQoL 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 to 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, it is recommended that both measures are used together. In severe dementia, only DEMQOL-Proxy should be used.

Further research with DEMQOL is needed to: (1) confirm these findings in an independent sample; (2) evaluate responsiveness; (3) investigate the feasibility of use in specific subgroups and in economic evaluation; and (4) develop population norms. Additional research is needed to address the psychometric challenges of self-report in dementia and validating new dementia-specific HRQoL measures.

Publication

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NHS R&D HTA Programme

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