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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**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 $\geq 10$) 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**

The research findings from the NHS R&D Health Technology Assessment (HTA) Programme directly influence key decision-making bodies such as the National Institute for Clinical Excellence (NICE) and the National Screening Committee (NSC) who rely on HTA outputs to help raise standards of care. HTA findings also help to improve the quality of the service in the NHS indirectly in that they form a key component of the ‘National Knowledge Service’ that is being developed to improve the evidence of clinical practice throughout the NHS.

The HTA Programme was set up in 1993. Its role is to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and provide care in the NHS. ‘Health technologies’ are broadly defined to include all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care, rather than settings of care.

The HTA programme commissions research only on topics where it has identified key gaps in the evidence needed by the NHS. Suggestions for topics are actively sought from people working in the NHS, the public, consumer groups and professional bodies such as Royal Colleges and NHS Trusts. Research suggestions are carefully considered by panels of independent experts (including consumers) whose advice results in a ranked list of recommended research priorities. The HTA Programme then commissions the research team best suited to undertake the work, in the manner most appropriate to find the relevant answers. Some projects may take only months, others need several years to answer the research questions adequately. They may involve synthesising existing evidence or designing a trial to produce new evidence where none currently exists.

Additionally, through its Technology Assessment Report (TAR) call-off contract, the HTA Programme is able to commission bespoke reports, principally for NICE, but also for other policy customers, such as a National Clinical Director. TARs bring together evidence on key aspects of the use of specific technologies and usually have to be completed within a limited time period.

The research reported in this monograph was commissioned by the HTA Programme as project number 97/17/16. As funder, by devising a commissioning brief, the HTA Programme specified the research question and study design. The authors have been wholly responsible for all data collection, analysis and interpretation and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors’ report and would like to thank the referees for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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