CHARTERED PHYSIOTHERAPISTS WORKING WITH OLDER PEOPLE

Outcome measures for Quality of Life in Dementia:

DEMQOL
DEMQOL-PROXY

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DEMQOL and DEMQOL Proxy:

Summary

Measures:
Patient reported quality of life in people with dementia

Description:
DEMQOL is a 28 item self reported / interviewer administrated measure
DEMQOL Proxy is a 31 item measure for use with carers

Who is it for?
People with mild to moderate dementia (MMSE ≥ 10)

Properties:

Reliability:
Good internal consistency and test – re-test reliability

Validity:
Moderate

Training:
Time to read the instruction manual.
If training is requested, information about this can be accessed through http://www.kcl.ac.uk/iop/depts/hspr/research/ciemh/mha/demqol/index.aspx

Equipment:
The survey tool

Time to complete:
Unknown, advice to take breaks of up to 10 minutes during if person struggling

Good things about it:
Specific measure for this population

Limitations:
Requiring further evaluation into its properties

Quality of Life measures in Dementia

Patient reported quality of life measures are beginning to be more widely used in clinical practice and have been recommended by the 2008 NHS review and by the CSP. However, one area where it has been difficult to capture heath related quality of life (HRQL) issues has been in patients with dementia. There has been concern shown about the validity of using non specific quality of life measures in people with dementia (Banerjee 2009). However, the same authors also acknowledge that the use [of dementia specific measures] may still remain experimental due to a lack of data on key aspects such as responsiveness, but there are positive signs that these instruments can capture HRQL accurately.

As such, AGILE felt it was appropriate to examine the properties of a dementia specific measure. Taking advice from dementia specialist physiotherapists and after a review of the available literature the DEMQOL and DEMQOL-PROXY appeared to have good psychometric properties and clinical applicability. Other measures that could be considered for use include:

- PDS
- The Dementia Quality of Life Instrument (DQOL)
- Pleasant Events Schedule-AD
- The Quality of Life in Alzheimer's Disease measure (QOLAD)
- The Alzheimer's Disease Related Quality of Life measure (ADRQL)
- SEIQoL (mild dementia)
- SEIQoL-DW (mild-moderate dementia)

It has been suggested that some measures are more appropriate for those in differing settings and in severity of disease progress (Schölzel-Dorenbos et al 2007) and you may wish to consider other specific dementia HRQL measures that are more appropriate to your setting and patients.

DEMQOL and DEMQOL-PROXY

Purpose
A conceptual framework was developed to look at health related quality of life issues in dementia (Smith et al 2005a). This demonstrated that some domains of health related quality of life for people with dementia were not captured by existing measures or by dementia specific measures that used only carer or proxy reports. As a result the research team developed the DEMQOL and DEMQOL-Proxy based on five domains: daily activities and looking after yourself, health and well-being, cognitive functioning, social relationships and self-concept. Gold-standard psychometric techniques were then used to develop DEMQOL and DEMQOL-Proxy (Smith et al 2005b).

Description
The DEMQOL is a 28 item self reported but interviewer administrated measure. The associated 31 item DEMQOL-Proxy is for use with carers. They both provide a method for evaluating health related quality of life in dementia. The measures 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 (Smith et al 2005b). There is an information manual which gives a clear description of how to administer the measures.

Having both self and proxy reporting sections is seen as a strength of the DEMQOL. Banerjee (2009) states that '*there would on balance appear to be true value in having measurement approaches to HRQL that enable both self-report and proxy-report data to be generated and for these to be deployed and understood together. At the very least they provide complementary views of the same construct*'.

Appropriateness
It is vital to use quality of life measures that are designed specifically for people with dementia; as such the DEMQOL fulfils this requirement.

Properties
DEMQOL has acceptable psychometric properties for people with mild to moderate dementia (defined as a Mini Mental State Examination (MMSE) score of >10) while DEMQOL-Proxy can be used for mild, moderate, or severe dementia (Banerjee et al 2009)

Reliability:
DEMQOL:
Internal consistency: Good (Cronbach Alpha 0.87)
Test – retest: Good (ICC 0.84)
DEMQOL-PROXY:
Internal consistency: Good (Cronbach Alpha 0.89)
Test – retest: Moderate (ICC 0.75)

Validity:
DEMQOL:
Convergent validity: Moderate correlation with other HRQL dementia measures
Construct validity: Inherent limitation due to problems of lack of validation of any similar measures

DEMQOL-PROXY:
Convergent validity: Moderate correlation with other carer reported measures
Construct validity: Inherent limitation due to problems of lack of validation of any similar measures

Responsiveness:
No data

Practical Implementation:
The DEMQOL has been used to show change following interventions for caregiver burden (Gavrilova et al 2009). Self-reported QoL assessments have been found to be feasible and appropriate for people with mild to moderate dementia (Trigg et al 2007).

Interpreting the score
A higher score indicates a better HRQL.
There is no convincing evidence that lower cognition or greater activity limitation is associated with lower HRQL. However, improvement in cognition may well be associated with improvements in HRQL is of importance. Interventions aimed at improving cognition may well result in improved quality of life for people with dementia (Banerjee 2009).

Limitations:
Results which are based on dementia patients' QoL self-ratings need to be interpreted with caution when anosognosia (impaired insight of an illness) is present (Berwig et al 2009). The DEMQOL is not suitable for those with severe dementia.

Availability:
Both measures are freely available for use and can be downloaded with instructions from
http://www.kcl.ac.uk/iop/depts/hspr/research/ciemh/mha/demqol/index.aspx

References

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