

Executive summary

General health status measures for people with cognitive impairment: learning disability and acquired brain injury

RP Riemsma*

CA Forbes

JM Glanville

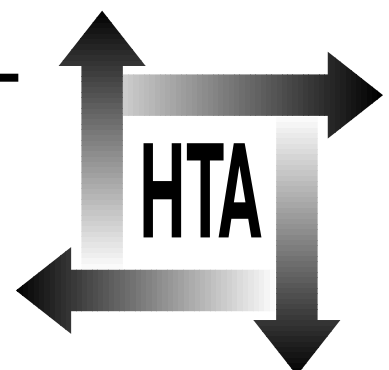
AJ Eastwood

J Kleijnen

NHS Centre for Reviews and Dissemination, University of York, York, UK

* Corresponding author

**Health Technology Assessment
NHS R&D HTA Programme**





Executive summary

Background

Currently there is a wide range of health status measures that aim to assess general health status in people with cognitive impairment. However, the validity and/or applicability to this patient group are largely unknown. This has implications for the assessment of treatment outcomes and rehabilitation, for prognostic purposes, for planning services, and for determining the benefits and adverse effects of health technologies targeted at these patient groups.

Objectives

- To identify the general health status measures that have been validated in patients with cognitive impairment.
- To assess the extent to which these measures have been validated.
- To draw out the implications of the findings for the use of existing measures and for future primary research in this area.

Methods

Selection criteria

Studies that assessed general health status in people with cognitive impairment due to acquired brain injury (traumatic brain injury, cerebrovascular accident or multiple sclerosis (MS)) or learning disability (LD) were included in the review. Studies that used general health status instruments measuring only one general health dimension, and studies that only featured participants with cognitive impairment due to dementia were excluded.

Search strategy

A wide range of relevant databases were searched for studies on cognitive impairment, general health status measures, and validation of health status measures. A handsearch of general health status bibliographies was also conducted.

Data were collected on the general health status measure used, the population characteristics, aims of the study, validity details, and conclusions.

Results

The review includes data from 71 studies, reported in 83 separate publications. In total 34 different general health status measures were described in the 83 publications, with the Sickness Impact Profile (SIP) and the Short Form-36 (SF-36) the most frequently used measures (20 and 19 studies, respectively). These studies included a total of 98 instrument validations, 52 of which definitely or probably included people with cognitive impairment. Six measures were extensively validated (quality scores ranged from 0.25 to 0.5, on a scale from 0 to 1) in studies in which more than 50% of the respondents were people with cognitive impairment. A further three measures were also validated in studies in which more than 50% of the respondents were people with cognitive impairment, but their level of validation was more limited (quality scores ranged from 0.1 to 0.2).

Five measures were validated in studies in which 20–50% of the respondents were cognitively impaired, which may limit their relevance to participants with cognitive impairment (quality scores ranged from 0.1 to 0.6). The SF-36 was also validated in two studies in which 20–50% of the respondents were cognitively impaired and the quality score was 0.3.

Finally, nine of the measures were only validated in studies in which less than 20% of the respondents were cognitively impaired. For these measures it was unclear whether the findings applied to people with cognitive impairment.

Conclusions

Very few measures have been validated specifically for cognitively impaired respondents. Studies where at least 50% of the respondents were cognitively impaired generally showed poorer validity results compared with studies with fewer cognitively impaired persons, indicating that general health status measures designed for the general population are not automatically suitable for people with cognitive impairment. The few measures that were specifically developed for people with cognitive impairment also reported

poor validity results. **Therefore, there are no validated instruments available for use in cognitively impaired respondents; existing measures, specifically designed for use in these populations, should be used with caution.**

The most promising measure is the MS-Quality of Life Interview (MS-QLI) for MS patients. The MS-QLI was thoroughly validated in 300 MS patients and the results were good, except for the 'social function' subscale. However, only 20–50% of the respondents in this study had cognitive impairment.

Most information on the validity of general health status measures was found in studies among people with LD. For these patients, six measures were found that have been validated in a populations where more than 50% of the respondents were cognitively impaired LD patients.

Implications for practice

- Existing general health status measures should be used with caution in individuals with cognitive impairments.
- There is no evidence to indicate the most suitable general health status measure for use in economic evaluations of cognitive impairment.
- There is little evidence to support the validity of proxy assessments in cognitively impaired populations.

Recommendations for further research

- There is a need for the development of new general health status measures for cognitively impaired people, particularly for people with acquired brain injury due to stroke, MS or trauma.
- Existing general health status measures, such as the SIP, SF-36, the EuroQol – 5 dimensions (EQ-5D) and the Nottingham Health Profile need to be validated for people with cognitive impairment. More research is needed into how these existing measures could be modified so

that they are more suitable for people with cognitive impairment.

- Currently there are no general health status measures for cognitively impaired populations available for use in economic evaluations. In general, the EQ-5D and Health Utilities Index were found to be superior, compared with other preference-based measures of health. The validity of these instruments needs to be assessed in cognitively impaired populations, as well as the feasibility of using choice-based techniques in people with cognitive impairments.
- Health status measures need to be validated for use by proxies in certain populations.
- Validity assessment of general health status measurements for people with cognitive impairment should be addressed in studies specifically designed for this patient population.
- Objective validated psychometric tests or a neurologist's diagnosis should assess the level of cognitive impairment. Separate analyses should be performed to assess the validity of the instrument for different levels of cognitive impairment.
- Validity assessment of general health status measures should include information on the choice of component items, sensibility, consistency, accuracy and suitability. When there is need for proxy assessments the instrument should be assessed for patient-proxy agreement and inter-rater agreement.
- Studies should include a large number of respondents with different levels of cognitive impairment, so that differences in the measure's validity for different groups of people with cognitive impairment can be assessed.

Publication

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NHS R&D HTA Programme

The NHS R&D Health Technology Assessment (HTA) Programme was set up in 1993 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.

Initially, six HTA panels (pharmaceuticals, acute sector, primary and community care, diagnostics and imaging, population screening, methodology) helped to set the research priorities for the HTA Programme. However, during the past few years there have been a number of changes in and around NHS R&D, such as the establishment of the National Institute for Clinical Excellence (NICE) and the creation of three new research programmes: Service Delivery and Organisation (SDO); New and Emerging Applications of Technology (NEAT); and the Methodology Programme.

Although the National Coordinating Centre for Health Technology Assessment (NCCHTA) commissions research on behalf of the Methodology Programme, it is the Methodology Group that now considers and advises the Methodology Programme Director on the best research projects to pursue.

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