Presenting the quality of life in genetic neuromuscular disease questionnaire (QoL-gNMD)

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Introduction

The Quality of Life in genetic Neuromuscular Disease questionnaire (QoL-gNMD) is a new Health-related quality of life measurement tool specifically designed for patients with a slowly-progressive neuromuscular disease that predominantly entails motor deficiency. The QoL-gNMD is structured in 3 domains: "Impact of Physical Symptoms", "Self-perception" and "Activities and Social Participation". Our objective was to develop a questionnaire easy to use in clinical settings and validate it with modern psychometric methods.

Methods

The french version of the QOL-gNMD was administered to patients recruited in 9 tertiary hospitals dedicated to genetic neuromuscular diseases. Each QoL-gNMD domain is measured on a T score metric i.e. a normal distribution with a mean of 50 and a standard deviation of 10. High values represent good quality of life. Standard errors of measurement were estimated using Items Response Theory. For each QoL-gNMD domain we estimated the conditional minimum detectable changes.

Results

A total of 315 patients were recruited for psychometric assessment. Each domain showed good psychometric properties (person separation index > 0.7, test-retest ICC>0.7) and fitted the partial credit model. Concurrent validity was assessed using the WHOQOL-BREF. Estimated conditional minimum detectable changes were calculated for each possible measure change.

Conclusion

The QoL-gNND is an operational validated questionnaire that can be used by both clinicians and researchers. Estimated conditional minimum detectable changes help identify differences for individual patients that are large enough to reflect a status change and motivate a modification of care. The english version of the QoL-gNMD is available but needs psychometric validation.