Validation of the HD-HRQOL (Huntington disease quality of life measure)

https://neurodegenerationresearch.eu/survey/validation-of-the-hd-hrqol-huntington-disease-quality-of-life-measure/

Principal Investigators

CARLOZZI, NOELLE E

Institution

UNIVERSITY OF MICHIGAN

Contact information of lead PI
Country

USA

Title of project or programme

Validation of the HD-HRQOL (Huntington disease quality of life measure)

Source of funding information

NIH (NINDS)

Total sum awarded (Euro)

€ 2,951,548.62

Start date of award

15/05/2012

Total duration of award in years

1

The project/programme is most relevant to:

Huntington's disease

Keywords

health related quality of life, Huntington Disease, Patient Outcomes Assessments, Quality of life, Validation

Research Abstract

DESCRIPTION (provided by applicant): The NIH Common Fund recognizes a “”pressing need to better quantify clinically important symptoms and outcomes, including pain, fatigue, and

quality of life."" The NIH Common Fund has led to an unprecedented number of large-scale initiatives to develop patient reported outcomes (PROs) for health-related quality of life (HRQOL) for use in: 1) the general population (funded by NIH); 2) adult epilepsy, stroke, amyotrophic lateral sclerosis, multiple sclerosis, and Parkinson's disease (funded by NINDS); 3) spinal cord injury (funded by NCMRR and NINDS); and 4) traumatic brain injury (funded by NIDRR and the VA RR&D). More recently, the NINDS has extended these measurement development efforts to include Huntington disease (HD)-a fatal, insidious, progressive neurodegenerative disease characterized by abnormalities in motor, cognitive, and psychiatric functions. HD is one of the more devastating neurological diseases, as symptoms gradually appear and worsen until eventually causing death. The effort to develop an HD-specific measure, called the ""HD- QOL,"" replicated state-of-the art qualitative methodology (utilized in the aforementioned PROs projects) to identify relevant HRQOL domains/themes in HD and develop items that reflect these domains/themes. Focus groups consisting of individuals with or at-risk for HD, family members and caregivers, and HD professionals were conducted to identify issues of HRQOL that were relevant for individuals with HD. Findings indicated the diverse issues (emotional, physical, social, cognitive and end of life) that confront individuals with HD. Specifically, findings demonstrated that while many of the constructs measured by the new PROs are relevant and important in this population, there is also a need for assessment of HD-specific HRQOL issues that are not already captured by these existing measurement systems (i.e., end of life issues, chorea, and speech and swallowing difficulties). As a result, items reflecting these HD-specific constructs were developed to complement the preexisting PRO initiatives. The proposed project will validate the HD-QOL and other relevant, newly developed PROs in a diverse sample of individuals with HD. Specifically, a state-of-the-art approach employing both classical and contemporary methods of test construction and validation – including Item Response Theory and computerized adaptive testing technology – will be used to develop a computerized adaptive test that permits brief and precise measurement of clinically relevant symptoms and functional limitations. In addition, this study will examine these measures' sensitivity and responsiveness to change over time. This new HD-QOL measurement system will allow clinicians to monitor patients by detecting small but important changes in HD HRQOL outcomes, allow researchers to conduct more efficient HD clinical trials (highly sensitive measures require fewer study participants), and allow patients to more effectively communicate their HRQOL concerns to their providers.

Lay Summary

Although the development of gene identification in Huntington disease (HD) has led to a push to find effective treatments for this fatal condition, current outcome measures lack the sensitivity needed to determine the effectiveness of such treatments on health-related quality of life (HRQOL). The purpose of this study is to determine the sensitivity of an HD-specific measure of HRQOL (the ""HD-QOL"") and of other new HRQOL measures developed for use in the general population. Ultimately, the findings from this study will provide clinically relevant information to providers, allow for more sensitive assessment of intervention-related change, and maximize the efficiency of clinical trials.

Further information available at:

Types:

Investments > €500k

Member States:

United States of America

Diseases:
Huntington's disease

Years:
2016

Database Categories:
N/A

Database Tags:
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