Cerebrospinal Fluid Research

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An Instrument to Measure the Health Status of Children with Hydrocephalus: The Hydrocephalus Outcome Questionnaire

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from 49th Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida
Barcelona, Spain, 29 June – 2 July 2005

Published: 30 December 2005

Cerebrospinal Fluid Research 2005, **2**(Suppl 1):S42 doi:10.1186/1743-8454-2-S1-S42

Background

The measurement of clinical outcome in pediatric hydrocephalus frequently ignores the substantial effect that the condition can have on a child's physical, emotional, cognitive and social health. Therefore, our group developed a quantitative health status measure, called the Hydrocephalus Outcome Questionnaire (HOQ), designed specifically for children with hydrocephalus. This was designed as a simple questionnaire to be completed by the child or child's parents.

Materials and methods

The standardized steps in the development of a health status measure were followed. Item generation involved health professionals and focus groups with parents of children with hydrocephalus. This created a comprehensive list of 165 unique health status items. To reduce this list, questionnaires were sent to 69 sets of parents to assess what they felt were the most important of these health issues. The 51 most important items were then selected to represent the following health domains: Physical, Social-Emotional and Cognitive Health. The 51-item questionnaire was then tested for reliability and construct validity, in another cohort of 90 sets of parents, against the following independent measures of specific components of health: Health Utilities Index (HUI-2), Wide Range Achievement Reading Test (WRAT), Strengths and Difficulties Questionnaires (SDQ), Functional Independence Measure for Children (WeeFIM)

Results

The HOQ took approximately 10–15 minutes for the parents to complete and demonstrated excellent test-retest reliability (0.93, 95% confidence interval (CI) 0.88–0.96), inter-rater reliability (0.88, 95% CI 0.79–0.93), and internal consistency (Cronbach's alpha 0.94). Construct validity was demonstrated by very good Pearson correlations of domain scores with their respective independent measures. The child-completed version of the HOQ also demonstrated very good reliability properties.

Conclusion

The HOQ for children with hydrocephalus has been developed and has demonstrated excellent reliability and validity properties. This will provide a valuable measurement tool for a wide range of clinical research projects in pediatric hydrocephalus. Using the HOQ, our group has begun a large-scale study to explore the determinants of health outcome in this population of children.