## **Hydrocephalus Outcome Questionnaire**

In the measurement of clinical outcome in pediatric hydrocephalus the condition's effects on a child's physical, emotional, cognitive, and social health are frequently ignored. The authors developed a quantitative health status measure, the Hydrocephalus Outcome Questionnaire (HOQ), designed specifically for children with hydrocephalus, which can be completed by the children's parents.

1. needs help dressing	0	0	0	0	0
2. needs help going to the washroom	0	0	0	0	0
3. has poor vision	0	0	0	0	0
4, has difficulty walking	0	0	0	0	0
5. needs a wheelchair	0	0	0	0	0
6. has difficulty participating in sports	0	0	0	0	0
7. has difficulty w/ handwriting	0	0	0	0	0
8. has poor physical balance	0	0	0	0	0
9, has difficulty tying shoelaces	0	0	0	0	0
10. gets tired cusily	0	0	0	0	0
11. has difficulty speaking	0	0	0	0	0
12. suffers from headaches	0	0	0	0	0
13, has frequent seizures	0	0	0	0	0
14, needs help bathing	0	0	0	0	0
15. needs help eating food	0	0	0	0	0
16. has difficulty participating in extracurricular activities	0	0	0	O	0
17. feets like he/she is stared at in public	0	0	0	0	0
18. has difficulty separating from me	0	0	ö	ö	O.
19. has many friends	0	ö	0	ö	ö
20, is treated as an equal by his/her peers	ö	õ	0	0	0
21, is able to visit friends	0	0	0	0	0
22. is solitary & keeps to him/herself	0	0	0	0	0
23. has difficulty recognizing the consequences of his/her actions	ö	ö	ö	0	ö
24. misses a lot of school due to illness	0	ö	ö	0	0
25. gets antious in social situations	0	0	ö	O.	0
26. has difficulty getting along w/ peers	0	0	ö	O.	0
27. is stry in public	õ	0	0	0	0
28. has difficulty playing w/ peers	õ	0	ö	0	0
29. is casily frustrated	0	0	0	0	0
30, has difficulty verbally expressing feelings	0	0	0	0	0
31, often feels stressed	0	0	0	0	0
32. is often irritable	Ô.	0	0	0	0
33. is unmotivated	õ	0	0	0	0
34, is concerned about his/her physical appearance	0	0	0	0	0
35. often feets sad	õ	õ	ö	0	0
36. worries about the future	õ	õ	ŏ	ö	ŏ
37, is often restless	õ	õ	ŏ	ö	0
38. lacks self-confidence	õ	õ	ŏ	õ	õ
39, overreacts to other people's illnesses	õ	õ	ŏ	0	ŏ
40; has a poor concept of time	õ	õ	ŏ	0	ŏ
41. has difficulty w/ math	õ	õ	ŏ	ö	ŏ
42, is well organized	õ	õ	ŏ	0	ŏ
43. has difficulty concentrating	õ	õ	ŏ	Ö	õ
44, is forgetful	õ	õ	ŏ	0	0
45, has difficulty performing several tasks in a row	ŏ	õ	õ	0	õ
45, has difficulty reading	ŏ	ŏ	ŏ	ö	o
47, is a slow learner	ŏ	ŏ	ŏ	ö	ö
48. needs instructions repeated	ö	ŏ	ö	ö	ŏ
49. forgets daily routines	ő	ŏ	ö	ö	ö
50. has difficulty learning new tasks	ő	ő	ö	ö	ö
50, has a short attention span	ő	ő	ő	ö	ö
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The Hydrocephalus Outcome Questionnaire (HOQ) is an established means of measuring quality of life, but the cognitive component of this questionnaire has never been formally compared with gold-standard neuropsychological test scores.

Kulkarni et al hypothesized that the HOQ Cognitive Health score would demonstrate a relatively strong correlation with neuropsychological test scores, whereas much weaker correlations would be seen for HOQ Physical and Social-Emotional Health scores.

A cross-sectional study of children with long-standing hydrocephalus presenting to The Hospital for Sick Children's Neurosurgery Clinic was performed between July 2006 and September 2008. Participating children and families completed the HOQ and a battery of 21 standard neuropsychological tests and questionnaires. Pearson correlation analysis was then performed.

A total of 83 patients (81% participation) was accrued; the mean age was  $11.5 \pm 3.4$  years (mean  $\pm$  SD) at the time of assessment. The mean age at hydrocephalus treatment was  $1.3 \pm 2.6$  years. The mean overall HOQ score was  $0.69 \pm 0.21$ . The HOQ Cognitive score had a moderate or strong correlation with 19 (90%) of 21 neuropsychological test scores, much more so than the HOQ Social-Emotional score (5 moderate or strong correlations, 24%) and the HOQ Physical score (1 moderate correlation, 5%). For 19 neuropsychological tests (90%), the HOQ Cognitive score had a stronger correlation than the other scores. The HOQ Cognitive score had particularly strong correlations with the Verbal IQ, List Learning, Behavior Problems, and Metacognitive Abilities components.

Data from a wide-ranging representative sample of children with long-standing hydrocephalus provide added evidence of the validity of the HOQ Cognitive score and the overall domain structure of the HOQ itself<sup>1)</sup>.

The aims of a study were to assess whether the Spanish version of the Hydrocephalus Outcome Questionnaire (HOQ) could be useful for the evaluation and comparison of outcomes in the patients in the authors' region with those in patients in other institutions and to analyze predictors of functional outcome in patients with a shunt. METHODS The authors performed this cross-sectional study between March 2015 and April 2016. All the parents of a pediatric patient with hydrocephalus who attended the Hospital Regional Universitario de Málaga neurosurgery outpatient clinic were invited to enroll in the study and complete the HOQ-Spanish version. Age at diagnosis and at the time of the study, clinical data, shunt complications, and socioeconomic factors were also recorded. A descriptive analysis was performed, and independent variables related to the HOQ scores were studied. RESULTS A total of 132 patients participated in the study (100% participation rate). The mean ages were 16.74 months (range 0-142 months) at diagnosis and 10.45 years (range 5-16 years) at the time of the study. The mean overall HOQ score was 0.68 (on a scale from 0 [worse] to 1.0 [best]). Factors related to a worse quality of life were seizures, motor or visual impairment, shunt infection, need for shunt revision, need for more than 2 shunt revisions (range 0-8 revisions), symptomatic overdrainage, and older age at the time of the study. CONCLUSIONS The HOQ-Spanish version is useful in the authors' region; the dimension scores found in this study were comparable to those previously reported by referral centers. Future goals should be to prevent shunt complications, routinely get children to reach functional status, and refer patients for adjuvant therapy promptly<sup>2)</sup>.

## 1)

Kulkarni AV, Donnelly R, Shams I. Comparison of Hydrocephalus Outcome Questionnaire scores to neuropsychological test performance in school-aged children. J Neurosurg Pediatr. 2011 Oct;8(4):396-401. doi: 10.3171/2011.7.PEDS1179. PubMed PMID: 21961548.

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