Quality of Life in Individuals Surgically Treated for Congenital Hydrocephalus During Infancy; Perspective of a Tertiary Care Hospital from a Developing Country

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Introduction

Congenital Hydrocephalus is the most common neurological defect in Pakistan. Most children are treated surgically. However, it involves long-term follow-ups and associated with numerous possible complications.

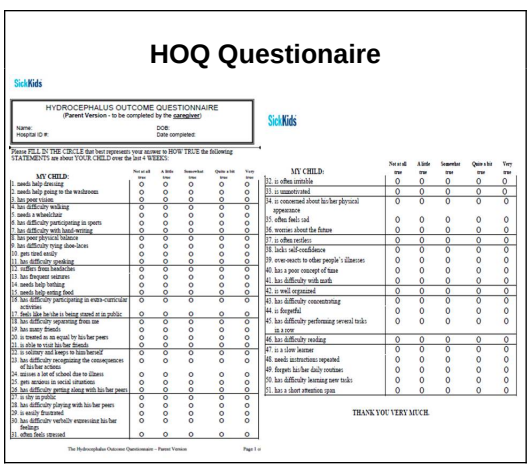
The rationale, to assess the Quality of life in adults, treated for Pediatric Hydrocephalus.

Methods

This was a cross-sectional study conducted at the tertiary hospital from 1995 to 2005.

A standard Hydrocephalus Outcome Questionnaire (HOQ) was used. Continuous data is presented as Means and Standard Deviation. Student T-test was used to compare means. p-value of < 0.05 was taken as significant.

HOQ Questionaire


SickKids

HYDROCEPHALUS OUTCOME QUESTIONNAIRE
(Parent Version - to be completed by the caregiver)

Name: DOB:
Hospital ID #: Date completed:

SickKids

Please FILL IN THE CIRCLE that best represents your answer to HOW TRUE the following STATEMENTS are about YOUR CHILD over the last 4 WEEKS.

MY CHILD:	Not at all true	A little true	Somewhat true	Quite a bit true	Very true
1. needs help dressing	○	○	○	○	○
2. needs help going to the washroom	○	○	○	○	○
3. has poor vision	○	○	○	○	○
4. has difficulty walking	○	○	○	○	○
5. needs a wheelchair	○	○	○	○	○
6. has difficulty participating in sports	○	○	○	○	○
7. has difficulty with hand-writing	○	○	○	○	○
8. has poor physical balance	○	○	○	○	○
9. has difficulty tying shoe-laces	○	○	○	○	○
10. gets tired easily	○	○	○	○	○
11. has difficulty speaking	○	○	○	○	○
12. suffers from headaches	○	○	○	○	○
13. has frequent seizures	○	○	○	○	○
14. needs help bathing	○	○	○	○	○
15. needs help eating food	○	○	○	○	○
16. has difficulty participating in extra-curricular activities	○	○	○	○	○
17. feels like he/she is being stared at in public	○	○	○	○	○
18. has difficulty separating from me	○	○	○	○	○
19. has many friends	○	○	○	○	○
20. is treated as an equal by his/her peers	○	○	○	○	○
21. is able to visit his/her friends	○	○	○	○	○
22. is solitary and keeps to him/herself	○	○	○	○	○
23. has difficulty recognizing the consequences of his/her actions	○	○	○	○	○
24. misses a lot of school due to illness	○	○	○	○	○
25. gets anxious in social situations	○	○	○	○	○
26. has difficulty getting along with his/her peers	○	○	○	○	○
27. is shy in public	○	○	○	○	○
28. has difficulty playing with his/her peers	○	○	○	○	○
29. is easily frustrated	○	○	○	○	○
30. has difficulty verbally expressing his/her feelings	○	○	○	○	○
31. often feels stressed	○	○	○	○	○

MY CHILD:	Not at all true	A little true	Somewhat true	Quite a bit true	Very true
32. is often irritable	○	○	○	○	○
33. is unmotivated	○	○	○	○	○
34. is concerned about his/her physical appearance	○	○	○	○	○
35. often feels sad	○	○	○	○	○
36. worries about the future	○	○	○	○	○
37. is often restless	○	○	○	○	○
38. lacks self-confidence	○	○	○	○	○
39. over-reacts to other people's illnesses	○	○	○	○	○
40. has a poor concept of time	○	○	○	○	○
41. has difficulty with math	○	○	○	○	○
42. is well organized	○	○	○	○	○
43. has difficulty concentrating	○	○	○	○	○
44. is forgetful	○	○	○	○	○
45. has difficulty performing several tasks in a row	○	○	○	○	○
46. has difficulty reading	○	○	○	○	○
47. is a slow learner	○	○	○	○	○
48. needs instructions repeated	○	○	○	○	○
49. forgets his/her daily routines	○	○	○	○	○
50. has difficulty learning new tasks	○	○	○	○	○
51. has a short attention span	○	○	○	○	○

THANK YOU VERY MUCH.

The Hydrocephalus Outcome Questionnaire – Parent Version Page 1 of 2

Table 1:

HOQ DOMAIN	Number (n)	Mean ± Standard Deviation
Physical health	31	0.47 ± 0.40
Social and emotional Health	31	0.45± 0.40
Cognitive Health	31	0.48± 0.43
Overall Health	31	0.46 ± 0.40

Mean HOQ Score

Results

45 patients, undergone insertion of VP shunt. Their mean age at presentation was 6.2 ± 10 months. Mothers of the surviving 31 patients filled the HOQ after mean follow-up. The mean HOQ Physical health score was 0.47 ± 0.40, mean Social-emotional health score was 0.45 ± 0.40, mean Cognitive health score was 0.48 ± 0.43 and the mean Overall health score was 0.46 ± 0.40.The most common complication was shunt blockage (33%) and shunt infection (24.4%). 18 patients (40%) were re-operated.Delayed milestones were reported in 22 (48.9%) children and had a statistically significant relation with physical health outcome (p-value = 0.036). No.of re-operations were significantly related to Social, Cognitive and Overall health outcomes (p-value = 0.003, < 0.001 and 0.016). Out of 14 died patients, 7 (50%) had shunt infections (p-value = 0.020) and delayed milestones were related to mortality.

Table 2:

HOQ SCORES AND DELAYED MILESTONES

HOQ DOMAIN	YES (N = 20)		NO (N = 11)		p VALUE
	Median	IQR	Median	IQR	
Physical	0.84	0.59	0.73	0.38	0.036
Social	0.70	0.41	0.90	0.22	0.35
Cognitive	0.74	0.50	0.92	0.06	0.79
Overall	0.74	0.43	0.85	0.19	0.060

Table 3:

FACTORS INFLUENCING MORTALITY

DEATH

FACTORS	p VALUE
Gender	1.0
Age	0.715
Seizures	1.0
Wound infection	1.0
Meningitis	1.0
Shunt Infection	0.020
Shunt Blockage	0.497
Delayed Milestones	0.003

- Mortality rate was observed to be 14/45(31.11%).
- Both groups (Deceased/ Alive) were compared for factors affecting mortality.

Table 4:

HOQ SCORES AND RE-OPERATIONS

HOQ DOMAIN	YES (N = 12)		NO (N = 19)		p VALUE
	Median	IQR	Median	IQR	
Physical	0.78	0.31	0.78	0.45	0.795
Social	0.80	0.29	0.71	0.55	0.03
Cognitive	0.81	0.22	0.91	0.20	<0.01
Overall	0.82	0.22	0.78	0.48	0.036

Conclusions

Congenital Hydrocephalus and its management in the developing countries pose a big social burden on the families. These children have a poor quality of life and dependency when compared to similar children in developed countries. This requires measures such as parental education, arranging long-term follow-up and multidisciplinary approach with involvement of neuro-rehabilitation specialist and pediatric psychologist to achieve better social outcomes in their life.

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