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Research Article

Parent Completed Assessment in follow up of Children with Hydrocephalus

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Abstract

Covid-19 induced pandemic has affected patient care to a great extent. Children with hydrocephalus and neural tube defects need regular follow up after surgical repair. During the pandemic, many children could not attend outpatient clinics for follow up. We used the 'Age and Stages questionnaires', a parent-completed tool for assessment of post-shunt hydrocephalus children (=25). We found this tool to be simple, cost-effective, easy to administer and effective in monitoring the developmental milestones of the babies. The tool can be used for routine use as a monitoring tool in other clinical situations as well.

INTRODUCTION

Children with hydrocephalus need regular monitoring of shunt associated complications. As regular follow up of such patients were not possible during the pandemic, the need and feasibility of a parent completed assessment tool to monitor their status was first discussed with the parents. The parents accepted the idea and volunteered to use the tool for periodic assessment of their children till normal services were restored in the hospitals. The parents liked the idea as they would be part of their children's treatment process and also because they did not have to travel long distances for routine post-operative follow up.

PATIENTS & METHODS

This cross sectional study was conducted between July and September in 2020. Forty children, operated for congenital hydrocephalus with ventriculo-peritoneal shunt (VPS) surgery were included in the study. Informed consent was obtained from parents and approval was obtained from the Institutional Ethics Committee. The original English version of Age & Stages Questionnaires (ASQ-III) as well as the translated Hindi and Assamese versions were sent to the parents and the parents were explained over phone about the process. 25 questionnaires were found to be completed and included in the study. Maternal history as well as the child's detailed history was recorded (Tables 1 & 2). Children with scores below cut off values were called for further investigation and intervention and in the hospital these scores were further corroborated independently by a clinical psychologist.

Table 1: Maternal history

Parity	Primi- 16	Multipara – 9
Maternal age	< 20 years – 6 >20 yrs – <35 yrs – 18 > 35 Yrs - 1	
Maternal illness	Gestational diabetes – 1 Hypertension – 1 Anaemia – 8 Previous bad obstetrical history - 1	

Table 2: Particulars of the study patients

Gender	Male - 16 Female – 9
Prematurity	11
Birth weight	< 2.5 kg - 14 (mean- 2.1 kg) ≥ 2.5 kg - 11(mean- 2.7 kg)
Age at surgery	< 1month - 6
	1M-24 M - 12
	1 year – 5 years - 6
	➢ 5 years - 1
Post-operative shunt infection/shunt block/shunt fracture - 7	
Patients needing revision surgery- 6 [2 needed > 1 revision]	

DISCUSSION

Babies born with hydrocephalus and neural tube defects need regular monitoring of growth and development following surgical repair. Ventriculoperitoneal shunt malfunction in children with hydrocephalus can often remain unrecognized in the early stage and could be diagnosed only with appropriate diagnostic test. Early recognition of developmental delay facilitates the

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implementation of prevention and intervention programs, which results in improvement in cognitive, behavioral, academic and adaptive functioning [1]. During the covid-19 pandemic, patients had stopped attending hospitals and outpatient services were suspended for long periods in many hospitals. In such a scenario, it would have been helpful if the parents could make periodic assessment of the developmental status of their children at home and communicate the outcome with the doctors, so that any deterioration of the status could be identified and managed at the earliest. Although many such parent-completed assessment tools are available, one of the biggest challenges is to choose a culturally sensitive screening tool, which include cultural perception of delay and/or disability and is easily adaptable across the various cultures / nations [2]. Among the developmental domains, social development is culturally specific and difficult to adapt, whereas the gross motor domain is easier to adapt culturally [3].

Eighteen children who had failed/borderline (11/7) ASQ scores were called for further evaluation and their scores obtained by the parents and the clinical psychologists were found comparable [Table 3]. In only one patient the parental score at home and that found by the psychologist differed by one point. Two children needed hospital admission: one for shunt revision and the other improved with adjustment of anticonvulsant medicines.

The ASQ was designed and developed by J. Squires et al and it was later recommended by the American Academy of Pediatrics for use in children. It is an excellent parent-completed tool used for evaluating five developmental domains: communication, gross motor, fine motor, problem-solving, and personal adaptive skills [4]. The latest version of ASQ-II has 21 sets of Questionnaires appropriate for children aged 1 – 66 months [4]. Juneja et al., used the Hindi version of ASQ on Indian children and validated it with the Developmental Assessment Scale for Indian Infants (DASII) [5]. The authors reported that the tool can help in identifying developmental delays both in high and low risk children, who can then be referred for more definitive diagnosis.

Table 3: Detail of parental scores (Low scores are shown in brackets in red colour)

Age group (no of children)	Area of assessment					
	Communi-cation	Gross motor	Fine motor	Problem-solving	Personal social	Overall response
7 months (4)	Normal in all	2 [2]	2 [2]	2[2]	4[0]	3 [1]
20 months (4)	Normal in all	2 [2]	2 [2]	4 [0]	4 [0]	0 [4]
27 months (7)	Normal in all	3[4]	5[2]	6[1]	7[0]	3[4]
36 months (6)	5[1]	2[4]	3[3]	2[4]	2[4]	2[4]
54 months (4)	3[1]	2[2]	2[2]	3[1]	3[1]	2[2]

Yue et al., has used the Chinese version of the same tool in rural Chinese children with good results [6].

In the present study, ASQ-II was chosen, as it could be administered to a wide age group and it was validated against DASII, which is considered gold-standard for Indian children. Further, we have observed that the agreement level between the parent and the clinical psychologist was very high. Thus, it can be concluded that the ASQ is a reliable and valid tool for periodic assessment of post-shunt hydrocephalus children at home. In institutions like ours where people need to travel long distances to attend hospitals and many parents have financial constrains, a parent-completed questionnaires could be an ideal assessment tool for the patients.

CONTRIBUTORSHIP STATEMENT

Dr. H.K. Dutta: Conception, design & planning, analysis of data, preparation of document, patient care.

Dr. Mauchumi Baruah: Planning, execution, communication with parents, supervised assessment in clinics, analysis of data.

Dr. Mridusmita Dutta: Communication with parents, translation of the tool, administration of the tool in clinics with clinical psychologist, collection of data, preparation of the draft.

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