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Ages and Stages Questionnaires: Feasibility of Online Survey for Postshunt Hydrocephalus Follow-Up

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Abstract

Objective Children with hydrocephalus need regular monitoring following shunt surgery. A parent-completed assessment tool was used successfully in follow-up of postshunt hydrocephalus children in the recent pandemic.

Methods The Ages & and Stages Questionnaires (ASQ) was sent via WhatsApp to parents of 40 postventriculoperitoneal (post-VP) shunt hydrocephalus children (7–57 months). Assessment was done by the parents/guardians in five domains over a period of 3 months. The completed questionnaires were analyzed and children with below the cutoff scores were called to the hospital for further evaluations and intervention if necessary.

Result Questionnaires of 25 children were found completed and analyzed. There were 16 males and 18 children had aqueductal stenosis and 11 had meningomyelocele. Eighteen children with failed/borderline (11/7) ASQ scores were called for further evaluation and in all but one the scores obtained by the parents and clinical psychologists were found comparable. Two children needed hospital admissions for shunt revision and adjustment of anticonvulsant medicines.

Conclusion The ASQ could be a useful tool, as parents can conduct the test at home and attend clinics in case of failed or borderline scores for further developmental assessment and/or intervention. This can be used as a routine monitoring tool in other clinical situations as well.

Keywords

- ages and stages questionnaires
- hydrocephalus
- development monitoring
- screening tool

Introduction

Children with neural tube defects and hydrocephalus need regular follow-up following surgical repair to assess their neurological status and for monitoring their growth and development. Symptoms of ventriculoperitoneal (VP) shunt malfunction are often subtle in the initial stage and remain unrecognized unless appropriate diagnostic test is used. During the recent pandemic, many postoperative patients could not attend hospitals for follow-up. The Ages and Stages Questionnaires (ASQ), a parent-completed assessment tool, was found to be most useful for the assessment of such children at home. Children who were found to have low scores needed to visit the hospital for further investigation and intervention.

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Table 1 Demographic characteristics of the study group (N = 25)

| Gender: M:F | | 16:9 |
|-----------------------------|--------------------------------------|-------------------|
| Birth weight | <2.5 kg | 14 (mean: 2.1 kg) |
| | ≥2.5 kg | 11 (mean: 2.7 kg) |
| Prematurity | 11 | |
| Type of hydrocephalus | Aqueductal stenosis | 18 |
| | Postmeningomyelocele | 7 |
| Age at surgery | <1 mo | 6 |
| | 1–24 mo | 12 |
| | 24–60 mo | 6 |
| | >60 mo | 1 |
| Postoperative complications | Nil | 15 |
| | Minor: skin infection, post-op ileus | 3 |
| | Shunt infection/shunt block/fracture | 7 |
| No. of revision surgery | No revision | 18 |
| | 1 revision | 4 |
| | ≥2 revisions | 2 |

Study Objective

The aim of this study was to evaluate the feasibility and reliability of parent-completed assessment tools for postoperative follow-up in children suffering from hydrocephalus.

Materials and Methods

This was a cross-sectional study conducted between July and September 2020. Twenty-five children aged between 7 and 57 months who were diagnosed with congenital hydrocephalus and underwent a VP shunt surgery were included in the study. Informed consent was obtained from the parents of all the enrolled children. Approval was obtained from the Institutional Ethics Committee.

Assessment Tool

The ASQ-3 (ASQ, 3rd edition) questionnaire was translated into Assamese language and back-translated to English. This procedure was repeated until the back translation matched the English versions. Both English and Assamese versions were provided to the parents, so that they could use either of the languages they felt comfortable with. Assessment was done in five domains: communication, gross motor, fine motor, problem-solving, and personal-social. Age-specific overall scores in 8 to 10 categories were also assessed.

Inclusion Criteria

Children operated for congenital hydrocephalus with a minimum 6-month postshunt period were included. Children suffering from other illnesses were excluded from the study.

Study Design

The ASQ-3 (English & Assamese versions) were sent via WhatsApp to 40 parents chosen as per the inclusion

criteria. The parents were explained in detail about the procedure over phone and how the different domains should be scored in the ASQ form. Thirty-three parents responded; however, only 25 questionnaires were found to be completed and included in the study. Children with scores below the cutoff values (in any of the domains) were called for further investigation and intervention. The ASQ-3 assessments of these children were repeated at the hospital by the parents under supervision of the doctors and then they were independently assessed by the clinical psychologist and the values were corroborated with those performed by the parents.

Results

The children were divided into five age groups: 4 in the 8 ± 1 month age group; 4 in the 20 ± 1 month group, 7 in the 27 ± 1.5 month group; 6 in the 36 month (34.5–39 months) group; and 4 in the 54 ± 3 month group. There were 16 males; 11 children had a mean birth weight of 2.7 kg and 14 had a mean birth weight of 2.1 kg (**Table 1**). The cause of hydrocephalus was aqueductal stenosis in 18 children and meningomyelocele in 7 children. Sixteen children were first-borns and in 7 cases, the mother's age was either younger than 20 years or older than 35 years (>Table 2). Eighteen test children with failed/borderline (11/7) ASQ scores were called for further evaluation and their scores obtained by the parents and the clinical psychologists were found to be comparable (>Tables 3 and 4). In only one patient, the parental score at home and that of the clinical psychologist differed by 1 point. Two children needed hospital admission and one of them needed shunt revision during this period. The other did well with adjustment admitted child anticonvulsant medicines.

Table 2 Parental status

| Primiparous mother | 16/25 | 64% |
|-------------------------------|----------------------------|-----|
| Maternal age | <20 y | 6 |
| | 20-29 y | 15 |
| | 30-35 y | 3 |
| | >35 y | 1 |
| Mother's antenatal history | Gestational diabetes | 1 |
| | Hypertension | 1 |
| | Anemia | 8 |
| | Previous abortion | 2 |
| Mother's literacy | Illiterate | 2 |
| | Primary level | 12 |
| | Secondary level | 8 |
| | Undergraduate/postgraduate | 3 |
| Father's literacy | Illiterate | 3 |
| | Primary level | 11 |
| | Secondary level | 10 |
| | Undergraduate/postgraduate | 2 |
| Parental socioeconomic status | Middle | 4 |
| | Lower middle | 12 |
| | Lower | 9 |

Statistical Analysis

Because of limited data, we used a nonparametric test, namely, Wilcoxon signed-rank test, to compare the scores of the parents and the clinical psychologist (>Table 4). For comparison, the mean scores and standard deviation are also presented in the table.

Discussion

Follow-up of postshunt hydrocephalus children is needed to assess the status of the shunt functioning and to assess children's development. Preventive and intervention programs can be initiated early to obtain satisfactory outcome provided shunt malfunction is detected early. This further results in improvement in the child's cognitive, behavioral, academic, and adaptive performance. In low-income countries, many postshunt patients do not come for regular follow-up at hospitals or clinics because of geographical or economic barriers. Very often developmental milestones are significantly delayed when they report at the hospitals. During the recent COVID-19-induced pandemic, patients stopped attending hospitals because of fear of getting infected, and in many hospitals, routine outpatient services were suspended for long periods. 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 in status could be identified and managed at

the earliest. Many tools have been developed to monitor the developmental milestones of children with parentcompleted questionnaires. One of the biggest challenges is to choose a culturally sensitive screening tool that includes cultural perception of delay and/or disability and is well accepted by the people.² Studies have shown that among the developmental domains, social development is culturally specific and difficult to adapt, whereas gross motor domain is easier to adapt culturally.³

The American Academy of Pediatrics (AAP) recommends mandatory assessment of the developmental status of all children.³ However, in many developing countries, parents and caregivers remain ignorant of the child's developmental deficit and its adverse consequences⁴. The ASQ, designed and developed by J. Squires and D. Bricker, is an excellent parentcompleted tool used widely by physicians across the world.^{5–8} The tool has been recommended by the AAP. The ASQ is simple, cost-effective tool, used for children between the ages of 4 and 60 months for evaluation of five developmental domains: communication, gross motor, fine motor, problem-solving, and personal adaptive skills. The parents' assessment of their children using this tool has been found accurate and reliable. 10

The latest version of ASQ, ASQ-3, has 21 sets of questionnaires, appropriate for children between the ages of 1 and 66 months.² Juneja et al used the Hindi version of ASO on Indian children and validated it with the Developmental Assessment Scale for Indian Infants (DASII). The authors found strong test characteristics for detecting

Table 3 Ages and Stages Questionnaires (ASQ) scores obtained by parents at home

| ASQ-3 | Sl. no | Area | | | | | | |
|-----------|--------|--------|---------------|----------------|---------------|-----------------|-----------------|-----------------------------------|
| age group | | | Communication | Gross motor | Fine motor | Problem solving | Personal-social | Overall response |
| 7 mo | | Cutoff | 33.06 | 30.61 | 40.15 | 36.17 | 33.84 | YNNNNNN |
| | 1 | | 45 | 35 | 45 | 45 | 50 | YNNNNNNN |
| | 2 | 1 | 35 | 30 | 40 | 35 | 40 | YNNNNNN |
| | 3 | 1 | 35 | 30 | 30 | 35 | 40 | NYNNNNNN |
| | 4 | 1 | 35 | 35 | 45 | 40 | 40 | YNNNNNN |
| 20 mo | | Cutoff | 20.50 | 39.89 | 36.05 | 28.84 | 33.36 | YYYYN-NNNN |
| | 5 | | 40 | 25 | 30 | 35 | 35 | YYY <mark>N</mark> NNNNN |
| | 6 | 1 | 50 | 40 | 45 | 40 | 40 | YYY <mark>N</mark> NNNNN |
| | 7 | 1 | 40 | 35 | 30 | 35 | 40 | NYNNNNNN |
| | 8 | 1 | 45 | 40 | 45 | 45 | 50 | YNNNNNNN |
| 27 mo | | Cutoff | 24.02 | 28.01 | 18.42 | 27.62 | 25.31 | YYYY-NNNNN |
| | 9 | | 40 | 25 | 15 | 35 | 35 | YYY <mark>N</mark> NN Y NY |
| | 10 | 1 | 35 | 25 | 20 | 35 | 40 | YYYYNNNNY |
| | 11 | 1 | 50 | 30 | 25 | 40 | 45 | YYYYNNNNY |
| | 12 | 1 | 50 | 30 | 20 | 45 | 50 | YYYYNNNNY |
| | 13 | 1 | 30 | 25 | 15 | 25 | 30 | YNYNNNNYY |
| | 14 | 1 | 50 | 40 | 35 | 40 | 50 | YYY Y NN N NN |
| | 15 | | 45 | 25 | 20 | 40 | 45 | YYYYNNYNY |
| 36 mo | | Cutoff | 30.99 | 36.99 | 18.07 | 30.29 | 35.33 | YYYYY-NNNNN |
| | 16 | | 20 | 25 | 5 | 25 | 30 | YNNYN-NNYYY |
| | 17 | 1 | 40 | 40 | 25 | 35 | 40 | YYYYY-NNNNN |
| | 18 | | 40 | 35 | 15 | 30 | 35 | YNYYN-NNNNN |
| | 19 | 1 | 40 | 35 | 15 | 30 | 35 | YNYYN-NNNNN |
| | 20 | | 50 | 40 | 25 | 35 | 40 | YYYYY-NNNNN |
| | 21 | 1 | 40 | 35 | 20 | 30 | 35 | YNYYN-NNNNN |
| 54 mo | | Cutoff | 31.85 | 35.18 | 17.32 | 28.12 | 32.33 | YYYYY-NNNNN |
| | 22 | | 20 | 25 | 5 | 25 | 30 | YNNYNNNYYY |
| | 23 |] | 45 | 40 | 35 | 35 | 45 | YYYYYNNNNN |
| | 24 | 1 | 40 | 35 | 15 | 30 | 35 | YNYYNNNNNN |
| | 25 | 1 | 45 | 40 | 30 | 35 | 40 | YNNYNNNYYY |

Note: In the overall responses, Y (yes) or N (no) depends on whether or not the child fulfils the criteria mentioned in the form. Failed scores are marked red. Normal cutoff values are marked blue. Black coloured ones are observed values within normal range.

developmental delay in children aged 18 to 24 months with fairly high sensitivity (83.3%) and good specificity (75.4%). The authors recommend the use of the tool for screening in both high- and low-risk children before referral for more definitive diagnosis. Yue et al 12 used the Chinese adaptation of the ASQ-3 among 1,831 children from rural China aged 5 to 24 months and validated the tool against the Bayley Scales of Infant and Toddler Development-III. The study, however, found the tool to be unsuitable for children below 13 months of age and in children whose primary caregiver is not their mother. In the present study, which was conducted among postshunt hydrocephalus children,

there was high agreement in ASQ scores of the parents and the clinical psychologist.

Khan et al used the Development Screening Questionnaire (DSQ), another parent-completed tool, to screen the neurodevelopmental status of Bangladeshi children from birth to 24 months of age.¹³ The DSQ has 24 age sets with 8 questions per set related to 8 functional domains: gross motor, fine motor, vision, hearing, cognition, socialization, behavior, and speech. Any child found to be positive on one or more functional domain is considered "screen positive." The tool was further validated against the "Rapid Neurodevelopmental Assessment" tool, which is considered the gold standard.¹³

Table 4 Comparison of scores obtained by parents and clinical psychologist

| Age groups | 7 то | | | 20 mo | | | 27 то | | | 36 то | | | 54 mo | | |
|---|------------|--------------------------|------------------------|---------------------------------|--------------------------|------------------------|----------------------------------|----------------------------------|------------------------|------------------------------------|----------------------------------|------------------------|--------------------------------|--------------------------|-----------------|
| Domains | Parent | Clinical psychologist | <i>p</i> -value Parent | Parent | Clinical psychologist | <i>p</i> -value Parent | Parent | Clinical psychologist | <i>p</i> -value Parent | Parent | Clinical psychologist | <i>p</i> -value Parent | Parent | Clinical psychologist | <i>p</i> -value |
| Communication 37.5 (5) 37.5 (5) | 37.5 (5) | | >0.05 | >0.05 43.8 (4.8) 42.5 (2.9) | | > 0.05 | > 0.05 42.9 (8.1) 42.9 (6.4) | 42.9 (6.4) | > 0.05 | 38.3 (9.8) | > 0.05 38.3 (9.8) 38.3 (9.8) | > 0.05 | > 0.05 37.5 (2.9) 27.5 (2.9) | 27.5 (2.9) | > 0.05 |
| Gross motor | 32.5 (2.9) | 32.5 (2.9) 32.5 (2.9) | >.05 | >.05 35 (7.1) 35 (7.1) | 35 (7.1) | > 0.05 | 28.6 (5.6) | > 0.05 28.6 (5.6) 29.3 (6.1) | > 0.05 | > 0.05 35 (5.5) | 35 (5.5) | > 0.05 | > 0.05 35 (7.1) | 35 (7.1) | > 0.05 |
| Fine motor | 40 (7.1) | 40 (7.1) 41.25 (4.8) | >0.05 | >0.05 37.5 (8.7) 38.8 (7.5) | 38.8 (7.5) | > 0.05 | 21.4 (6.9) | > 0.05 21.4 (6.9) 21.4 (5.56) | > 0.05 | > 0.05 17.5 (7.58) 17.5 (7.58) | | > 0.05 | > 0.05 21.25 (13.8) 20 (12.25) | 20 (12.25) | > 0.05 |
| Problem-solving 38.8 (4.8) 38.8 (4.8) | 38.8 (4.8) | | >0.05 | >0.05 38.6 (4.8) 37.5 (2.9) | 37.5 (2.9) | > 0.05 | > 0.05 37.1 (6.3) 37.1 (6.3) | 37.1 (6.3) | > 0.05 | 30.8 (3.8) | > 0.05 30.8 (3.8) 30.8 (3.8) | > 0.05 | > 0.05 31.3 (4.8) 31.3 (4.8) | 31.3 (4.8) | > 0.05 |
| Personal-social 42.5 (5.0) 41.3 (2.5) > 0.05 41.3 (6.3) 41.3 (6.3 | 42.5 (5.0) | 41.3 (2.5) | >0.05 | 41.3 (6.3) | 41.3 (6.3) | > 0.05 | 42.1 (7.6) | > 0.05 42.1 (7.6) 42.1 (6.4) | > 0.05 | 35.8 (3.8) | > 0.05 35.8 (3.8) 35.8 (3.8) | > 0.05 | > 0.05 37.5 (6.5) 37.5 (6.5) | 37.5 (6.5) | > 0.05 |

Among the few parent-completed screening tools developed in India for Indian children, the Lucknow Development Screen (LDS), the New Delhi-Development Screening Questionnaire (ND-DSQ), and the Trivandrum Developmental Screening Chart (TDSC) have been used for screening of the neurodevelopmental status in children of various age groups with acceptable results. 14-16 The tools are age specific and two of these tools (LDS and TDSC) are reported to be suitable for screening among community-level workers. 14,16

Choosing the right screening tool appropriate for the culture and language used by the participants is important. Garg et al reported that use of even simple, easy-to-use parent-completed developmental tools for routine surveillance in the Australian state of New South Wales has remained suboptimal because of various reasons.¹⁷ In contrast, implementation of the AAP guidelines for developmental screening by health professionals have shown remarkable improvement resulting in up to 85% of eligible children being screened for developmental problems.¹⁸

In the present study, ASQ-3 was chosen, as the ASQ can be administered to a wide age group and it has been validated against DASII, which is considered the gold standard for Indian children. Further, we observed that the agreement level between the parents and the clinical psychologist was very high. The Wilcoxon signed-ranked test shows that the difference in the scores of the parents and the clinical psychologist with respect to different dimensions and age is not statistically significant (p > 0.05). In some of the cases, the scores obtained by the parents and the clinical psychologist are almost similar. Thus, it can be concluded that the ASQ is a reliable and valid tool for periodic assessment of postshunt hydrocephalus children at home.

Conclusion

During the recent pandemic, the ASQ was found to be a useful tool, as parents could conduct the test at home and only those children whose scales were not appropriate for his or her age or whose scale deteriorated over time needed to visit the hospital or clinic for further developmental assessment and intervention.

Authors' Contribution

H.K.D. was responsible for study conception, design, questionnaire administration, analysis, and manuscript preparation. M.B. contributed to questionnaire administration, evaluation, communication with parents, coordination with psychologist, and manuscript preparation. M.D. contributed to questionnaire administration, communication, clinical and psy-chological evaluation, and preparation of tables.

Conflict of Interest None declared.

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