Original Article

North India Childhood Cataract Study - The real scenario and causes of surgical delay of pediatric cataract

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Purpose: The study sought to describe the clinical presentation pattern of pediatric cataracts and factors leading to delay in surgery at a tertiary care center in North India. **Methods:** A cross-sectional, interview-based study was conducted from January 2020 to October 2020, that included pediatric patients <12 years, with unilateral or bilateral congenital or developmental cataract. A pre-validated questionnaire was used to record data. The parameters recorded were age at first symptoms, age at diagnosis of cataract, age at surgery, laterality of cataract, first symptom, first family member noticing the abnormality, the morphology of cataract, association of perinatal complications, family history, systemic diseases, and cause (s) of delay in surgery. **Results:** A total of 89 patients were included. The mean age of subjects was 4.75(±3.51) years. A white pupil was the most common symptom (64.04%) and appeared in infancy in 30.3% of cases. Parents first detected the problem in 60.67%, and the pediatrician was the first medical contact in 11.23% of cases. The median (IQR) delay period between diagnosis of cataract and cataract surgery was 4 (3–6) months, the major causes were long GA waiting (30.33%), and delay due to systemic ill health (14.61%). **Conclusion:** Parental education on cataract detection is recommended to help in the timely detection and hence, improved outcomes of pediatric cataract surgery. Pediatricians, consulted for any systemic illness, have the role of the second most important contact in the detection of pediatric cataract.

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Pediatric cataract is the leading cause of childhood blindness in the world. Globally, 14% of childhood blindness has been reported to be due to pediatric cataracts.[1] Untreated pediatric cataract causes a tremendous social, economic, and emotional burden to the child, family, and ultimately to society.[2]

Depending on the age of onset, childhood cataracts can be classified as congenital or developmental cataracts. Cataracts present at birth are known as congenital cataracts. However, sometimes they may be diagnosed later. Cataracts that develop in the first decade of life are known as developmental cataracts.

Based on a meta-analysis by Wu *et al.*,[3] the prevalence of pediatric cataract has been estimated to be around 2.2 to 13.6 per 10,000 children worldwide. The prevalence was found to be highest in Asia with 7.43 per 10,000 children.[3] Population-based studies by Dandona *et al*. and Dorairaj *et al*. of a South Indian population have shown that lens-related complications are responsible for blindness in 15.3% and 42.9% of total blind children.[4-7]

The detection of cataracts requires some basic awareness among parents. A cataract may go undetected if parents lack this education. Distance from health care facilities (HCFs), lack of awareness, and low socio-educational status of parents are common reasons for the delay in the presentation of pediatric cataracts.[8,9] High cost and lack of facilities in small towns and villages of North India are other major factors responsible for delay in surgical intervention after presentation.

We, at a tertiary care center, diagnose and treat a considerable number of pediatric cataracts and can provide a glimpse into the disease burden in northern India as ours is a referral center for pediatric cataracts in North India. In this study, we aim to define the pattern of presentation of pediatric cataracts, identify the first medical contact (FMC) and risk factors, and identify the causes of delay in presentation and subsequent delay in surgery in patients with pediatric cataracts.

Methods

A cross-sectional, interview-based study was conducted from 1 January 2020 to 31 October 2020. Patients were referred to the lens clinic of our center from the outpatient department, other ophthalmologists or pediatricians were screened by a senior ophthalmologist and those with visually significant cataracts were advised surgery and date of admission. All pediatric patients aged ≤12 years, with unilateral/bilateral congenital or developmental cataracts, who were admitted to the pediatric cataract inpatient ward of Dr Rajendra Prasad Centre for Ophthalmic Sciences, for cataract surgery were included in

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the study. Informed consent was obtained from the parents or legally authorized representatives (LARs) of all participants for participation in the study. The study was conducted as per the tenets of the Declaration of Helsinki. The examination findings of all of the patients were noted and parents or guardians of all of these children were interviewed face-to-face by a single investigator using an open-ended questionnaire. Parents and siblings of all children were also screened with dilated distant direct ophthalmoscopy.

The Consensus-Based Checklist for Reporting of Survey Studies (CROSS) was followed for the preparation of the manuscript. The questionnaire was adapted and modified from the study conducted by Sen *et al*.[8] It included 17 questions. The participants were interviewed by a single interviewer. In the interview, details were collected about demography (age, gender), birth order, perinatal history, symptoms, systemic and ocular history, family history and socioeconomic status. The questionnaire contained questions about the first symptom identified, the first family member identifying the symptom and cause (s) of a delay from the parent's perspective [Appendix 1].

Data was analyzed using Stata 14.2, student's *t*-test was used to compare the difference in the presentation based on gender, and one-way analysis of variance (ANOVA) was used to study the effect of birth order on the pattern of presentation.

Results

A total of 89 children (64 males, 25 females) were included in the study. The overall mean age at presentation was 4.75(±3.51) years. Both females and males presented at similar mean age ($P = 0.427$, student's *t*-test). 70 patients (78.65%) presented with bilateral cataract. No significant correlation was found between laterality and gender ($P = 0.701$, Chi-squared test). Positive family history could be elicited in 13 cases (14.61%). History of consanguineous marriages was elicited in 5 cases (5.62%).

Perinatal History: 22 children (24.72%) had a premature birth, and 23 (25.48%) were delivered through a caesarean section. The majority of cases were identified as institutional deliveries (82.11%) and had an uneventful perinatal period (76.02%). Perinatal complications included sepsis in three children, anemia in five, and low birth weight in ten babies. Eight babies required neonatal intensive care unit (NICU) admission in the immediate postpartum period, while one child had a history of birth asphyxia.

Birth Order: Most children (40) belonged to the first birth order. Twenty-eight children were of second birth order. The rest (21) belonged to the third birth order or higher. Table 1 shows the mean age of presentation with respect to birth order. Age of presentation did not vary with the birth order ($P = 0.688$, one-way ANOVA).

Socioeconomic Status: Most (43) of the children belonged to the upper-lower socioeconomic strata of the society. Thirty-one children were from lower-middle and nine were from the upper middle. Families of two children had upper and four had lower socio-economic status. We could not find any significant association between delay 1 or delay 2 and socioeconomic status. Familial reluctance toward surgery and financial issues were causes of delay in 16 patients. All of those belonged to the lower or upper-lower socioeconomic strata.

Table 1: Correlation between birth order and age of presentation

Birth order	Mean age(±SD) of presentation
1	4.72(±3.41)
2	4.41(±3.52)
3 or higher	5.33(±3.71)

P=0.688 (one-way ANOVA). SD- Standard Deviation

Table 2: Morphology of childhood cataract

Morphology	*n* (%)
Total Cataract	40 (44.94%)
Lamellar Cataract	27 (30.34%)
Nuclear Cataract	6 (6.74%)
Posterior Subcapsular	4 (4.49%)
Membranous	3 (3.37%)
Cataracta Pulverulenta	2 (2.25%)
PFV with Cataract	2 (2.25%)
Microspherophakia	1 (1.12%)
Complicated Cataract	4 (4.49%)
Total	89 (100%)

Table 3: First society member detecting cataract and the symptom identified

Society members detecting cataracts first	*n* (%)	Symptoms detected	*n* (%)
Parents	54 (60.67%)	White Pupil	57 (64.04%)
Pediatrician	10 (11.23%)	Deviation of Eyes	8 (8.99%)
Relatives	7 (7.87%)	Low Vision	9 (10.11%)
		Holding objects close to the face.	5 (5.62%)
		Not making eye contact when expected to make it.	4 (4.49%)
Grandparents	6 (6.74%)	Poor Academic Performance	7 (7.87%)
Teacher	5 (5.62%)	Photophobia	2 (2.25%)
Ophthalmologist	4 (4.49%)	Discharge from Eyes	2 (2.25%)
Family Physician	3 (3.37%)	Noted Due to Referral	4 (4.49%)
Total	89 (100%)		89 (100%)

Table 4: Causes of delay in surgery

Causes of delay	*n* (%)
Long GA waiting	27 (30.33%)
Systemic ill health	13 (14.61%)
Parents seeking second opinion	11 (12.36%)
Parental Reluctance for Surgery	10 (11.23%)
Cost of Surgery	6 (6.74%)
Misled by Local Practitioners	10 (11.24%)
No Delay felt	12 (13.48%)
Total	89 (100%)

Type of Cataract: 52 (58.43%) out of 89 children had congenital cataracts, 27 (37.08%) had developmental cataracts, and 4 (4.48%) had an acquired cataract. Based on morphology, the different presentations were total cataract, nuclear cataract, membranous cataract, posterior subcapsular cataract, cataracta pulverulenta, persistent fetal vasculature with cataract, microspherophakia, and complicated cataract. Table 2 shows the distribution of morphology of cataracts in our patients.

First Symptom: Symptoms were first noted by parents in 54 patients and grandparents in 6 patients. Other relatives identified the abnormality in seven patients, while teachers played a key role in five patients.

The most common reported symptom was a whitish reflex in the eyes in 57 cases. Deviation of eyes was noted in eight patients. Abnormal ocular movements were noted in 35 children (39.3%); however that was the presenting complaint in only ten children. Seven patients were detected due to their poor academic performance, while another five were noted to hold objects close to their faces. Four patients were identified by their inability to make eye contact when expected. Other reported complaints were photophobia, discharge from the eyes, and inability to open eyes. Four children were directly referred to our center for screening by a pediatrician [Table 3].

FMC: Cataract was identified by a family physician in three cases. Ophthalmologists made a primary diagnosis of cataracts in as few as four children.

Ten patients were diagnosed by a pediatrician while they were admitted to the NICU for systemic conditions. The systemic diseases identified were congenital rubella (n = 4), neonatal jaundice (n = 1), Down syndrome (n = 1), birth asphyxia (n = 1), birth trauma (n = 1), and neonatal hypoglycemia with septic shock (n = 1). The rest of the patients (n = 72) were identified by family members or relatives and presented to ophthalmologists for management.

Time course from diagnosis to surgery and surgical delay: The median (IQR) age of onset of symptoms was 24 (6–72) months, while the final diagnosis was made at the median (IQR) age of 26 (8–72) months. The median (IQR) age at surgery was 32 (14–76) months.

The median (IQR) delay between onset of symptoms and formulation of diagnosis was 2 (0–4) months. The median (IQR) delay between diagnosis and surgery was 4 (3–6) months. The total delay from onset of symptoms to surgery was estimated to be 7 (4–10) months.

The major cause of surgical delay was the long general anesthesia (GA) waiting time in 27 patients. Other important causes were systemic ill-health of the child, parents seeking a second opinion, parental reluctance for surgery, and the cost of the surgery. Parents were misled by local practitioners in ten cases. There was no significant delay felt in 12 out of 89 patients. Table 4 shows the important causes of delay.

Discussion

Pediatric cataract is an avoidable cause of blindness and has remained a priority in the World Health Organization's (WHO) Vision 2020: The Right to Sight. Poor socioeconomic status, nutritional deficiencies, lower literacy levels, and lack of adequate vaccination coverage in women of childbearing age are important factors responsible for the higher prevalence of pediatric cataracts in low-income countries.

The mean age of presentation in our patients was 4.75(±3.51) years. This goes in hand with the mean age of 4.42 years by Khanna *et al*.[10] in a study in south India. Studies from central India reveal a slightly higher mean age of presentation: 7.63 years by Nikhil *et al*.[11] and 7.82 years by Sen *et al*.[8] An even higher age of presentation of nine years was reported in a study based in rural Maharashtra.[12] In a study conducted in northern India, again the majority of patients were 5–10 years of age at the time of presentation.[13] Poor socioeconomic status and long distance from the hospital are usually associated with late presentation.

In our study, the cause of pediatric cataracts could not be identified in 66.29% of children. Various studies in different parts of India have also shown pediatric cataracts to be idiopathic in 24%–73% of cases, making idiopathic the most common cause of childhood cataracts.[13–16]

7.2%–42.3% of cataracts have been reported to be hereditary.[13–15] Our study on similar lines shows positive family history in 14.61% of children. Another important cause of childhood cataracts is intra-uterine infections. 4.49% of children in our study had congenital rubella syndrome. Johar *et al*., El Fkih *et al*. and Mohan *et al.* have also reported rubella to be causative in 4.7%, 4.6%, and 5% of their study samples, respectively.[14,15,17] TORCH positivity was reported in 33.41% of cases in a study conducted in South India.[16]

Stress in the perinatal period is also an important cause of developing cataracts in childhood.[18] In our patients, two children (2.25%) had a history of septic shock in the immediate postpartum period. One child (1.12%) each had neonatal hyperglycemia, neonatal jaundice, and a history of birth trauma.

No child had metabolic disorder, while one child (1.12%) was diagnosed with Down Syndrome.

Most of the cataracts were bilateral (77.53%). Haargaard *et al*.[18] reported a higher prevalence of bilateral cataracts in males. However, no such association was reported in our patients. Katibeh *et al*.[19] have reported that the rate of pediatric cataract surgery in males is almost 10% higher than in females. The proportion of males getting operated on in our series is also significantly higher. The probable cause seems to be gender neglect. In our experience, we have noted that most females with cataracts present at an age of around 15–19 years. (A potential marriageable age especially in population strata belonging to poor socioeconomic status.).

The most common presentation pattern of pediatric cataracts in our patients was a congenital cataract in 58.43% of cases, followed by developmental cataracts in 37.08% of cases. Khanna *et al*.[10] reported data from children operated in a tertiary institute in Hyderabad with almost similar findings: congenital cataracts in 58.2% and developmental cataracts in 38% of patients. In a study from a rural Maharashtrian population, Gogate *et al*.[12] reported a lower prevalence of congenital cataract (12.4%) cases than developmental cataracts (38%).

Total cataracts (44.94%), lamellar cataracts (30.34%), and nuclear cataracts (6.74%) were the most common morphologies identified in our patients. There is wide heterogeneity in the morphology of pediatric cataracts in various studies worldwide, with the most common morphologies being total, nuclear and lamellar.[20–22]

Few studies in the past have worked upon the presenting complaints of children with cataracts. Zhu *et al*.[23] have reported leukocoria in 38.8%, decreased vision in 41.3%, and deviation of eyes in 18.1% of cases. The respective values for the above three features were 34.7%, 23.5%, and 12.0% as per the work of Nagamoto *et al*., while Yang *et al*. reported white pupil in 31.5%, poor vision in 33.3%, and strabismus in 10.8% of cases.[24,25]

These studies report leukocoria as the presenting feature in approximately 1/3rd of cases.[24,25] However 2/3rd of our patients presented with leukocoria. Complaints of diminution of vision were also less prevalent (10.11%) in our patients as compared to the above studies. The percentage for squint (8.99%) was, however, similar to the results of the above authors.

Parents and grandparents are the primary contacts to diagnose the pathology. Parents identified the disease in 60.67% of our cases, making them the most important target for awareness activities for the early detection of cataracts. This result of ours is in unison with the findings of other studies.[9,12] Literacy levels of parents, especially the mother, is a key determining factor for delay in diagnosis. The grandparents or other relatives primarily identified cataracts in only one-sevenths (nearly 15%) of cases.

Children with developmental cataracts have reasonably good vision and hence are often detected late. Teachers have played an important role in diagnosing developing cataracts. School vision screening programs should be reinforced with adequate training of the teachers to enhance the detection of visual disability.

Cataract was identified by a pediatrician in ten cases and a family physician in three cases. 11.23% of patients were diagnosed by their pediatrician during their stay in the hospital or other checkups due to some systemic diseases. General pediatricians also can play an important role in the early management of cataracts in such patients as they are FMCs of children with cataracts. Screening for cataracts should be a routine practice in all patients admitted to NICU or other pediatric wards. All pediatric cases attended by a pediatrician or a family physician for any systemic condition should be screened for cataracts as an opportunistic screening strategy. The ophthalmologist was the least important primary point of contact in just 4.49% of cases.

In ideal scenarios, unilateral congenital cataracts should be operated on by around 6 to 8 weeks of age and bilateral congenital cataracts by around 10 weeks of age to get acceptable visual outcomes.[26,27] However this is often unachievable in real-world situations. In our cases, symptoms could be identified in 30% of all cases in infancy; however, only 22% could be operated on in their first year of life. In our patients, the median (IQR) total delay was 7 (4–10) months. The median delay in other studies were reported to be 18 months: 9 months for congenital cataracts and 24 months for developmental cataracts.[9]

Ours is a tertiary care center and caters to the need of the majority of north Indian states. The facility of pediatric cataract surgery is not fully functional in other government hospitals, and most people cannot afford surgery in private hospitals. This leads to a large backlog of cases, making long GA waiting time the major cause of delay in our cases. Other major causes include systemic ill health of the child, parents seeking a second opinion, cost of surgery and parental reluctance towards surgery. Due to high surgical costs, dependency on the public health schemes that offer cost exemption is high. Cataract surgery for children less than one year of age is done free of cost under Janani Shishu Suraksha Karyakram (JSSK), a public health scheme in India, launched by the Government of India. For older kids, parents need to pay for the surgical costs unless they have their child's names registered under other schemes providing exemption of charges like PMJAY (Pradhan Mantri Jan Aarogya Yojna) or BPL (Below Poverty Line) card schemes. The parents who belong to the poor socioeconomic status need to go through extensive formalities in the offices of governmental authorities for getting these cards made to claim free surgery. This too adds to another factor causing a delay in surgery. Parents had limited information about treatment options, and even local practitioners were not skilled in the management of pediatric cataracts. This also led to a significant delay in as many as ten cases (11.24%).

The contributory factors for delay in presentation in pediatric cataracts were evaluated in an eastern African study: developmental cataracts, far distance from the hospital and low socio-educational status of the mother.[9] They reported early presentation in those having a sibling, probably due to good experience of the parents of the expected level of achievement of sight at a young age.[9] Positive family history was found in 14.61% of our patients; however positive family history did not correlate with an early presentation in our patients (P = 0.943, student's t-test). Based on the findings from this study, we recommend that information, education, and communication (IEC) activities should target parents and primary school teachers for early diagnosis and management of childhood cataracts, which is crucial for a better prognosis. IEC activities targeting those who live far-off thus have the potential for reducing the surgical delay time. Newborn red reflex test should be made a routine in all obstetric and pediatric setups. Primary HCWs should also be trained in this simple newborn red reflex test. This will allow early detection of cases. The lack of safe and effective GA services in the periphery leads to an increased burden on tertiary health care centers, which causes prolonged GA waiting time. Public health interventions should target providing safe and effective GA services in peripheral hospitals to allow timely management of the disease.

Our study has many limitations: small sample size, no evaluation of correlation with outcomes (owing to cross-sectional design) and recall bias. We also could not depict the exact picture owing to the ongoing COVID-19 pandemic during the study period. However, this is the first study that has characterized the pattern of clinical presentation of childhood cataracts in North India in a tertiary care hospital.

Conclusion

Though early diagnosis and management are associated with good visual outcomes, delay in diagnosis and hence, surgery

is a significant public health challenge. Efforts should be made to raise awareness amongst the target groups and provide treatment facilities in a decentralized manner at the district hospitals to improve the prognosis of childhood cataracts.

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Conflicts of interest

There are no conflicts of interest.

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Appendix 1: The Pre-validated Questionnaire	
Child's Name बच्चे का नाम	
DOB/Age जन्म तिथि/ उम्र	
Gender लिंग	
Relation of interviewee to child साक्षात्कार दाता का बच्चे से संबंध	
Phone No. फोन नो.	
Address पता	
Distance from hospital (in km) अस्पताल से दूरी	
Antenatal or Perinatal event of significance गर्भ या जन्म के दौरान कोई परेशानी	
Birth order जन्म क्रमांक	
Associated ocular comorbidities आँखों की अन्य समस्या	
Family history परिवार में अन्य लोगों को ऐसे परेशानी	
Socioeconomic status [(Education+Occupation+Income) of the head of the family] सामाजिक आर्थिक स्थिति	

First Symptom noted पहला देखा गया लक्षण 1 = child photophobic in sunlight तेज धूप में बच्चे को परेशानी होना 2 = deviation of eyes or ABN ocular movements आँखों का तिरछापन/ अप्राकृतिक तरीके से हिलना 3 = noted whitish opacity आँखों में सफ़ेदी दिखना 4 = not making eye contact आँख से आँख न मिलाना 5 = holding objects close to face वस्तुओं को बहुत करीब रख कर देखना 6 = not concentrating in studies पढ़ाई में ध्यान न देना 7 = discharge / inability to open eyes आँखों से पानी आना या आँखें न खोलना 8 = refered किसी अन्य विभाग से जांच के लिए भेज जाना	

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