

Causes of delayed presentation of pediatric cataract: A questionnaire-based prospective study at a tertiary eye care center in central rural India

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Purpose: To find out the sociodemographic, sociocultural, and socioeconomic factors leading to delay in pediatric cataract surgery and its impact on final visual outcome. **Methods:** A prospective interview-based analytical cohort study was conducted on 156 children aged 0–16 years with either unilateral or bilateral congenital/developmental cataracts. Caregivers were interviewed using a pretested validated questionnaire. Time intervals between recognition by a caregiver to consultation were denoted as Delay-1 and between consultations to surgical intervention as Delay-2. Spearman's rank correlation was used to determine the presence of correlation between causes of delay and visual outcome. **Results:** The mean age of presentation was 7.78 ± 4.34 years. Mothers were the first informant of the problem ($n = 110$, 70.5%). Out of 156 children, only 8 (5.1%) children presented to the hospital within 1 month by caregivers and 26 (16.7%) children underwent surgery within 2 months of advice. About 22 (14.1%) children had total cumulative delay of 1–6 months, 11 (7%) had delay of 6–12 months, and 115 (73.71%) had delay of >12 months. The most common cause identified for Delay-1 was unawareness in 41 cases (26.28%), however, for Delay-2 major factor responsible was cost ($n = 38$, 24.35%). The median preoperative visual acuity was 1.31 logMAR and median postoperative visual acuity at 4 weeks was 0.61 logMAR. ($P < 0.001$) Less age at surgery, upper socioeconomic status, less time delay, and better preoperative vision were positively correlated to better visual outcomes. **Conclusion:** Delay in presentation for childhood cataract surgery remains a significant problem in central rural India. Delay in surgery is multifactorial which includes unawareness, cost, misdiagnosis, self-treatment, distance from the hospital, lack of family support, and poor socioeconomic status.

Key words: Delayed presentation, pediatric cataract, socioeconomic status

Childhood blindness is a high priority of VISION 2020: Right to Sight initiative of World health organization, as it contributes to about 5% of total blindness which is equal to 1.5 million blind children all over. Nearly 14% of this blindness is due to pediatric cataract.^[1] The prevalence of childhood cataracts is 1–15 cases per 10,000 live birth in developing countries and in India it contributes about 7.4–15.3% of childhood blindness.^[2]

Congenital and developmental cataracts not only reduce visual perception but also interfere with normal visual development, thus potentially causing a severe degree of stimulus-deprivation amblyopia.^[3] Hence, early removal of pediatric cataracts is advocated.^[4,5] Factors leading to a persistent shortfall or delay in early surgical removal of cataract in children in developing countries include cost of surgery,^[6–10] lack of awareness,^[8,9,11] fear of surgery,^[9,10,12] concerns about the quality,^[9,10,11] self and herbal treatment by traditional healer,^[13] distance from care providers,^[6–10,12] gender discrimination, age, and lack of family support.^[8]

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These barriers are important to address as the development of visual impairment at an early age has far-reaching implications on a child's life. As well as delay in surgical intervention leads to subnormal outcomes causing a large burden on the family as a unit and society/nation as a whole.^[13,14] Our hospital as a tertiary eye care center with children eye care facility is catering mostly rural population of central India and seeing children of cataract with either delayed presentation or refusal for surgery even after diagnosis.

Therefore, the aim of this study is to find out the sociodemographic, sociocultural, and socioeconomic factors leading to delay in pediatric cataract surgery and its impact on final visual outcome.

Methods

This was a prospective interview-based analytical cohort study conducted from September 2016 to August 2017. About 156 children with age range from birth to 16 years with congenital

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or developmental cataract presented to our institute for the first time were enrolled. Informed consent was obtained from the guardians of all participants. The study was initiated after approval from the institutional review board and in accordance with the tenets of the Declaration of Helsinki.

Caregivers were interviewed immediately on admission using a pretested validated questionnaire which was partly taken from the study done by Claudia *et al.* in Brazil.^[15] [Appendix-1] The questionnaire on health-seeking behavior was taken from it. The interview covered basic sociodemographic and economic information of the household. The economic status of children's families was classified into five categories using the Modified Kuppusswamy Socioeconomic Scale.^[16]

Time intervals between recognition by a caregiver to presentation to the hospital were denoted as Delay-1. The interval between presentations to the hospital to surgical intervention was represented as Delay-2. The cumulative interval from recognition of problem by caregivers to surgery was represented as Total Delay (Delay1 + Delay2).

All children underwent a comprehensive ophthalmic examination including visual acuity, refraction, anterior segment, and posterior segment assessment. Age-appropriate visual acuity assessment was performed on every child using Teller's grating cards or central, steady, and maintained fixation (CSM) method in infants, Cardiff's acuity test in children aged 1–3 years, LEA symbol in children 3–5 years and Tumbling E or Snellen's chart in children aged more than 5 years. After cataract surgery, follow-up was scheduled at 4 weeks and parameters noted were: visual acuity, anterior and posterior segment evaluation, and spectacle prescription given with appropriate near addition. Postoperative vision gain at 4 weeks has been adjudged without amblyopia treatment.

Descriptive statistical analysis was conducted using the mean \pm standard deviation, median, and percentages. Tables and graphs were used to display data as appropriate. Friedman's one-way ANOVA test was used to compare the visual outcome i.e., LogMAR scores preoperative and postoperative at a 1-month interval. Spearman's rank correlation was used to determine the presence of correlation and strength of association between variables. The determinants of outcome were identified accordingly. IBM SPSS version 17 was used to conduct statistical analysis.

Results

Around 156 children with congenital/developmental cataract were included in the study. The mean age of presentation was 7.78 ± 4.34 years of which 11 were infants. A number of unilateral cataracts were 64 and bilateral cases were 92. Sociodemographic and economic details of the household-based interview were shown in Table 1.

Caregivers recognized the eye problem after 1 year of age in 118 children (75.6%). Mothers were the first informant of the problem in 110 (70.5%) cases. In 111 (71.1%) children, care-givers recognized the child's eye problem either as low vision or whitish pupillary reflex in eyes.

Out of 156 children, only 8 (5.1%) children presented to the hospital within 1 month of recognition by caregivers and

26 (16.7%) children underwent surgery within 2 months of surgical advice by ophthalmologist. The duration of Delay-1 and Delay-2 were shown as pie charts in Fig. 1. Nearly 22 (14.1%) children had total cumulative delay of 1–6 month, 11 (7%) had a delay of 6–12 months and 115 (73.71%) had delay of >12 months. Median delay for unilateral cataract was 2.5 years which is higher than the bilateral cataract (Median – 1.5 years).

Causes of Delay-1 and Delay-2 were identified in a questionnaire-based interview. The most common cause identified for Delay-1 was unawareness about problem in 41 cases (26.28%), however, for Delay-2 major factor responsible was cost ($n = 38$, 24.35%). Details of different causes of Delay-1 and 2 with their numbers were shown in Table 2. The most common cause for cumulative delay in bilateral cataract was cost or no family support ($n = 29$, 31.52%) and for unilateral cataract was unawareness of disease ($n = 31$, 48.34%).

Visual acuity outcome and its correlations with variables

A total of 248 eyes of 156 children were operated. The median preoperative visual acuity was 1.31 logMAR unit and median postoperative visual acuity at 4 weeks was 0.61 logMAR. ($P < 0.001$) Less age at surgery, upper socioeconomic status,

Table 1: Demographic details of patients with the socioeconomic status of household

Variables	Value or percentage
Age (years)	7.78 \pm 4.34
Gender (male/female)	1.28:1
Distance to hospital	
Near	10.3%
Far	89.7%
Socioeconomic status	
Upper	7%
Upper-middle	8.3%
Lower-middle	21.1%
Upper-lower	56.4%
Lower	7%
Family History of Childhood cataract	
Positive	11%
Negative	89%
Screening at birth	
Yes	13%
No	87%

Table 2: Cause of Delay-1 and Delay-2

Causes	Delay 1 n (%)	Delay 2 n (%)
Unawareness	41 (26.28%)	-
Did not know where to go	24 (15.38%)	-
Misdiagnosis	13 (8.33%)	-
Self-treatment	9 (5.76%)	-
Distance from hospital	13 (8.33%)	23 (14.74%)
Take care of other family member	7 (4.48%)	9 (5.76%)
No family support	4 (2.56%)	21 (13.46%)
Cost	32 (20.51%)	38 (24.35%)
Other factors	9 (5.76%)	15 (9.61%)
Fear of surgery	-	13 (8.33%)
Small age of child	-	22 (14.10%)

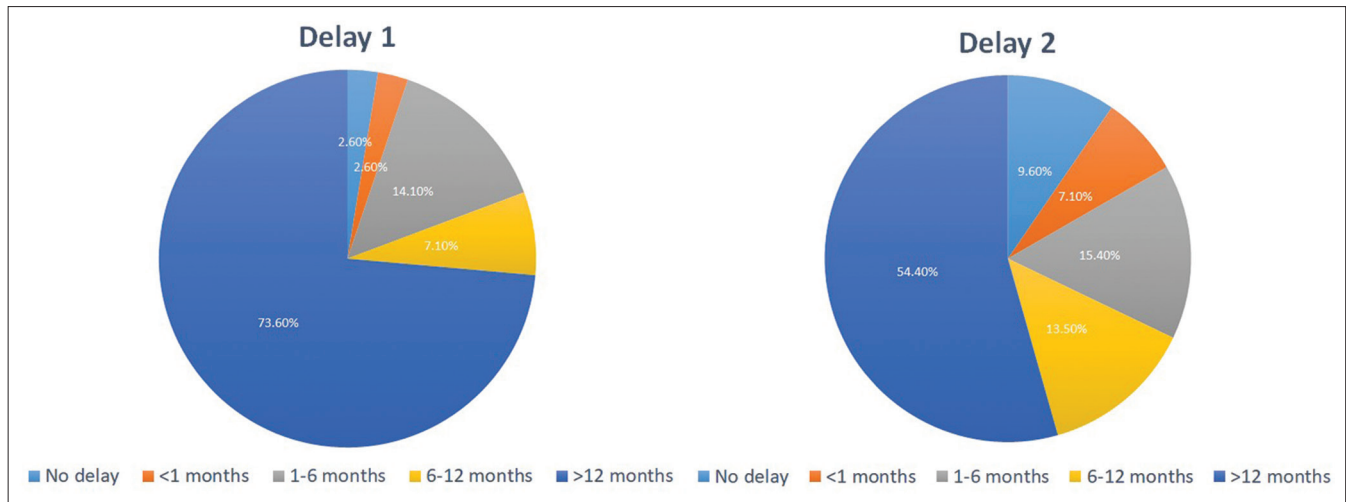


Figure 1: Pie -chart showing the number of children with different time delay for Delay-1 and Delay-2

less time delay between recognition, and presentation to the healthcare worker and better preoperative visual acuity were positively correlated to better visual outcomes. Table 3 shows the correlation between different variables with visual outcomes.

Discussion

Congenital and developmental cataracts are common types of cataracts in the Indian population. Since the critical period of vision development is up to 8 years of age, so any cataract that develops in early childhood interferes with normal visual development thus potentially causing amblyopia. Therefore, it is of great concern that any form of visually significant lens opacity should be recognized and removed as early as possible.^[17,18] Although all facilities and resources for surgical treatment for pediatric cataract are available in India, still childhood cataract contributes to 7.4 to 15.3% of childhood blindness in the country.^[2]

A majority of children were presented late to the hospital according to different studies done in India which were highlighted by Khanna *et al.*^[19] and Anushree *et al.*^[20] The mean age of presentation was 4.4 years and 7.6 ± 4.2 years in their studies respectively. In our study, the mean age of surgery was 7.78 ± 4.34 years which was higher than the abovesaid studies as most of our patients were of rural populations and they were not aware of the problem. However, previous studies did not focus on reasons for delayed presentation. In the present study, we have tried to find out the various factors causing delay in presentation and surgery of pediatric cataracts.

The major delay occurred between recognition by caregivers and presentation to the hospital. 94.9% (n = 148) presented after 1 month of recognition of problem in our study. The most common cause of this delay was unawareness (26.28%). In a study done by Mwendu *et al.*, they reported that families had inadequate knowledge about infant’s vision which contributed to the delayed presentation of these children to the hospital.^[21] Gogate *et al.* found that in 38.54% cases, the parents did not feel the need to take the child to hospital as they thought the child was seeing fine and does not need any medical or surgical help.^[22] In our study, unawareness can be attributed to the low

Table 3: Correlation of variables with improvement in LogMAR Score after 1 month as compared to preoperative vision

Variable	Spearman’s rho	P
Younger Age	0.3	<0.001
Upper Socio Economic Status	0.2	<0.05
Less Delay-1	0.201	0.012
Less Delay-2	0.236	0.003
Better pre-Operative visual acuity	0.7	<0.001

educational status of the people residing near our hospital as the head of the family was illiterate in 26.92% cases or had only primary education in 24.35% cases. A study conducted by Claudia *et al.* showed that 16.4% of parents had a low education which correlated positively with the delay in the presentation of the child to healthcare worker.^[15]

The mother’s educational status might have contributed to the delayed presentation in our study, as the literacy rate of females is only 60% in our area.^[23] This factor is important to address as mothers were the first ones to recognize some eye problems in their child (70.5%) but brought the child to healthcare worker only when she noticed decreased vision, which is a late symptom. The effect of the mother’s educational status on the child’s’ early presentation was also seen in few studies.^[15,21]

Another factor that led to delay was cost. In our study, 20.51% of parents recognized the child’s condition but did not go to the hospital because of the costs involved in traveling and treatment. Jaya Thakur *et al.* in Nepal reported that the cost of travel to the clinic, follow-up cost, and the wage-earning hours of the parents contributed significantly to the delay in cataract surgery of children.^[24] Similarly, Gogate *et al.* found out that the parents of 24.80% children could not afford travel to the hospital.^[22]

The other kind of delay seen in our study was the time delay between advice for surgery and surgical treatment in the hospital. About 82.69% of children were presented to the hospital for surgery after 2 months of surgical advice. The cost

was one the major reason for this delay as reported by 24.35% of the respondents. Nathan *et al.* found that free accommodation or financial support led to an early presentation to hospital for management.^[25] Erikson *et al.* advised the subsidized cataract surgery to shorten the Delay-2.^[26] Therefore, cost is an important factor that needs to be addressed because 63.46% of our study population belonged to lower socioeconomic groups. In 48.71% cases, the monthly income of the household was <5546 INR and 56.41% were daily wage workers.

The third most common factor that leads to delay in presentation to hospital in 8.33% cases and delay in surgical treatment in 14.74% cases was the distance between the residences of a child from the eye care center. In our study, 133 (95%) out of 156 children lived more than 50 km away from the hospital, out of which 30.7% lived more than 200 km away from the hospital. Gogate *et al.* reported 20.22% of children presented late because they lived far away from the hospital and did not have access to eye care facilities.^[22] Mewende *et al.* also showed an association between distance to hospital and delay in presentation.^[21]

Although the percentage of males (55.76%) and females (44.23%) presented to the hospital for cataract surgery were comparable, the majority of the children who presented early were males (87%). Erikson *et al.* found that girls were 1.9 times less likely to be brought to the hospital.^[26] Although previous studies have noted no gender predisposition to congenital cataracts, these findings could reflect the health-seeking behavior of the population in this region, wherein health issues in a male child are given priority.

In our study, only 13.46% of children were screened at birth for cataracts. This might have led to the delayed presentation of these children as shown by similar results of a study done in China where they emphasized the urgent need to strengthen neonatal screening programs.^[27] There will be a recall bias in adolescent children and their parents regarding "screening at birth" in our study. Neonatal screening for cataract has to be incorporated at the village level. This can be done by teaching the village health workers/ASHA worker by the simple red reflex test.

In our study, 10.8% of children had a positive family history, but none of them presented early. These findings were in contrast to findings from a study done in Tanzania^[21] wherein they found that parents having one child with history of cataract, had consulted to an ophthalmologist at an early age for their another siblings with similar problems. This fact again points to a higher percentage of unawareness about pediatric cataracts in our study population. Though we have not screened the other siblings, merely asking for a family history may not suffice in ruling out a familial cataract. Cataracts running in different generations of family may be picked up earlier due to aware parents/relatives. This can be a possible factor reducing the delay in some subjects.

Fear of surgery, small age, and no family support are also some of the contributing factors for the delay. Some caregivers came late because they had to take care of other family members. Similar other variables were seen by Gogate *et al.*^[22] This shows that delay in pediatric cataract surgery is multifactorial and measures have to be taken to overcome these factors.

The median preoperative visual acuity in our study was 1.3 log MAR units that improved to 0.6 log MAR units at 4 weeks after cataract surgery. This change in visual acuity was significant ($P < 0.001$). In our study, 85 (34.2%) eyes had visual acuity of <0.48 log MAR units (equivalent to 6/18 in Snellen chart) at 4 weeks. Similar improvement in postoperative visual acuity is also seen in other studies done in India. Anushree *et al.* reported that the percentage of eyes having vision <0.48 log MAR units increased from 3.4% to 27%.^[20] These figures show that, although there was a delay in cataract surgery in the majority of the children, still there is a possibility of improvement in vision, and thus these children should be operated as early as they come and adequately visually rehabilitated. In contrast, studies from the west have shown a better outcome. In our study, only 34.27% eyes had a postoperative visual outcome of <0.48 log MAR units. This percentage of children was lesser than results of the study done by Richard *et al.*^[28] in which 58% children had a postoperative vision <0.48 log MAR units. A study done by Nathan *et al.* had a postoperative visual outcome of <0.48 log MAR units in 40% of patients.^[26] You *et al.* showed that 46.8% of children had a visual outcome of <0.48 log MAR units.^[29] These studies had better outcome because the mean age of surgery was less and majority of the caregivers recognized the cataract within 6 months of age and brought the child early to hospital and also the interval between the examination and surgery was less than 2 months in majority of the cases.

Our study provides useful insight into the health-seeking behavior of parents of children presenting with developmental cataracts in central rural India. The major limitation of this study is that it is a hospital-based prospective study and not the community-based cross-sectional study which indeed reflects the population problems. Moreover, our setup is a tertiary care hospital so there might be a referral bias. We are yet to evaluate the other factors affecting visual outcomes in pediatric cataracts such as amblyopia, unilateral cataract, squint, and nystagmus which are known for poor visual outcomes. Our study was not a long term longitudinal study, hence, we have presented only an interim data and further studies are required to quantify the final visual outcome with all postoperative rehabilitation measures.

Conclusion

Our findings suggest that the delay in presentation for childhood cataract surgery remains a significant problem in central rural India even when high-quality surgical services are available within easy reach. Children living in remote areas, who cannot come to the hospital because of distance and poor socioeconomic conditions of their households, needs to be approached by developing bridging strategies that would link communities to hospital. Educational efforts to increase the knowledge of the caregivers about the pediatric cataract should also be warranted to ensure the early presentation of these children for cataract surgery.

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Conflicts of interest

There are no conflicts of interest.

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Appendix-1: Study questionnaire

Questionnaire

Study number _____

Hospital record number _____

A) Who was interviewed?

1. Mother 2. Father

Contact number: mother \ father

B) Child's name

C) DOB/Age:

D) Sex:

1. Male 2. Female

E) Address:

F) Distance from the hospital (in km):

1. <50 2.51–100 3.101–150 4.151–200 5. >201

G) Head of the family:

1. Mother 2. Father

H) Socioeconomic status: Score

(education + occupation + income)

Education Score

Profession

Graduate or postgraduate

Intermediate (11th–12th)

High school certificate (9th–10th)

Middle school certificate (6th to 8th)

Primary school certificate (up to 5th)

Illiterate

7
6
5
4
3
2
1

Occupation

Professional

Semi-professional

Clerical, shop-owner, farmer

Skilled worker

Semi-skilled worker

Unskilled worker

Unemployed

10
6
5
4
3
2
1

Monthly income of the family (in Indian currency)

> 36997

18498–36996

13874–18497

9249–13873

5547–9248

1866–5546

< 1865

12
10
6
4
3
2
1

I) Screening for cataract done after birth

1. Yes 2. No

J) When did some problem notice in child's eye?

1. at birth 2. Birth-1 month 3.1–6 months 4.6–12 months 5.>1 year

K) Who noticed the problem first?

1. Mother 2. Father 3. Other relatives 4. Teacher 5. Medical personnel

L) What was noticed first?

1. white pupil 2. watering 3. rubbing of eyes 4. low vision 5. deviation of the eye

M) Whom did you for help first?

1. Doctor 2. Nurse 3. Ayurvedic doctor 4. Village health worker 5. No one

N) When did you go for help first?

1. at birth
2. Birth-1month
3. 1-6 months
4. 6-12 months
5. >12 months

O) If the answer to the above question is more than 1 month, answer the following questions:

1. Did not know that some problem exists
2. Did not know where to go
3. Misdiagnosis
4. Traditional treatment/self-treatment
5. Long distance from hospital
6. Take care of another family member
7. No family support
8. Cost of treatment
9. Some other reason

Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No

P) Time elapsed between advice for surgery and posted for surgery

1. No time wasted
2. 0-2 months
3. 2-6 months
4. 6-12 months
5. >12 months

Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No

Q) If the answer to the above question is more than 2 months, then answer the following questions:

1. Fear of operation
2. The child is too small for operation
3. Large distance from hospital
4. No family support
5. Economic issues
6. Take care of another family member

other problems