

Tribal Odisha Eye Disease Study (TOES). Report # 8. Childhood cataract surgery and determinants of visual outcome in tribal districts

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Purpose: The purpose of this study is to describe the demographic profile, clinical features, visual outcomes, and follow-up patterns after successful cataract surgery in children from the tribal community in Odisha, India. **Methods:** We retrospectively reviewed records of tribal children aged 4 months–16 years, who underwent public health financed cataract surgery at our institute from January 1, 2015, to December 31, 2019. Collected data included demographic profile, clinical features, outcomes, and follow-up. Univariate and multivariate linear regression identified factors affecting the visual outcome at a 6-week follow-up. **Results:** During this period, a total of 352 children [536 eyes; mean age: 9.11 ± 4.4 years, 219 boys (62%)] underwent cataract surgery. The most common etiology and presenting complaints were idiopathic congenital cataract and decreased vision, respectively. In 304 children (86%), presenting best-corrected visual acuity (BCVA) was $<20/200$ (1.0 LogMAR), 113 (32%) had associated strabismus, and 57 (16%) had associated nystagmus. The public health agency did not sponsor postoperative follow-up, and only 195 (56%) and 61 (17.3%) children completed a 6-week and a 3-month follow-up, respectively. Median BCVA at 6-week and 3-month review was 20/125 (0.8, interquartile range [IQR], 0.2–2 LogMAR) and 20/60 (0.5, IQR, 0.25–1.35 LogMAR), respectively. **Conclusion:** This study showed that children from the tribal community presented late with poor presenting VA and had suboptimal visual outcomes with inconsistent follow-ups. Greater advocacy, delivery of care closer to the place of residence, and financial support for follow-up care could improve early detection, regular evaluation, and outcomes.

Key words: Congenital cataract, developmental cataract, the tribal population

Cataract is one of the leading causes of global blindness and visual impairment in children.^[1] The reported median prevalence of childhood and congenital cataract is 1.03 and 1.71/10,000 children, respectively.^[1] Unlike adults, childhood cataract requires early surgery and postoperative visual rehabilitation for a good visual outcome.^[2] Childhood cataract can have a tremendous impact on the socioeconomic status of individuals, their families, communities, and the country.^[3] But available data from India indicate that only 50% of children with cataract present early enough for surgery.^[4] Late presentation for surgery, inadequate follow-up, and poor postoperative visual outcome remains a challenge in low- and middle-income countries.^[4–8] Reported barriers to early surgery and optimum

care are lack of access to affordable eye care, inadequate knowledge, ignorance, and local beliefs.^[5,8–10] These challenges are further aggravated in the tribal populations in India, where primary health-care facilities are scarce, literacy levels are low, and socioeconomic conditions are poor.^[11] In India, many of the advanced eye care centers are located in urban areas and remain mostly out of the tribal community's reach. There are scant reports on pediatric cataracts in children from tribal populations in India.^[12] In this communication, we describe the demographic profile, clinical features, cataract morphology, visual outcomes, and follow-up patterns after cataract surgery in children from the tribal population of Odisha, India.

Methods

We performed a retrospective chart review of consecutive children, 4 months–16 years of age, from the tribal community who were screened in the community and underwent cataract surgery at a tertiary eye care center in Odisha, India, from January 1, 2015, to December 31, 2019. The study was approved

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by the Institutional Ethics Committee of the Institute (IEC: 2020-47-BHR-33) and adhered to the tenets of the Declaration of Helsinki.

Definitions

Tribal was defined as a collection of families bearing a common name, sharing common culture, language, history, and occupying common rural settings.^[13] *Consanguinity* was defined as marriage between second- or third-order cousins or uncle-niece. Children were classified to have *familial cataracts* if one of the parents/siblings had congenital cataracts in their childhood or lenticular opacity on slit-lamp examination (genetic testing was not performed due to economic constraints). Cataract was classified as *congenital* if the diagnosis was established before the first birthday and *developmental* if the diagnosis was more than 1 year. Additionally, all dense bilateral cataracts with invisible fundus or absorbed cataracts and/or nystagmus at presentation were also classified as congenital cataracts.

All patients underwent a detailed preoperative evaluation with comprehensive ocular and general physical examination, fundus examination with indirect ophthalmoscope when possible, and ocular ultrasonography (USG B-scan) where fundus examination was not possible. The parents were examined for any existing lenticular opacity/evidence of prior cataract surgery. Biometry was done in the outpatient clinic in cooperative children using a partial coherence interferometry system (IOL Master 500, Carl Zeiss Meditec, Jena, Germany) and in the operating room at the time of surgery in others using a hand-held keratometer (Nidek KM-500 Aichi, Japan) in non-cooperative children. Axial length was measured with portable contact A-scan biometry (Biomedix-Echolure 2, India) at the time of the surgery.

We had access to the clinical details, demographics, geographic location, and limited information about the socioeconomic constraints of patients/parents. The collected data included the demographic profile, type of cataract, etiology, clinical presentation, presenting visual acuity, fixation pattern, coexisting nystagmus and strabismus, type of cataract, surgical procedures, visual outcome, and follow-up pattern of all children. Genetic testing of the children or the family members was not done. The data were systematically entered in Microsoft Excel (Microsoft Inc., Richmond, USA) for analysis.

Surgical technique and follow-up: We used the standard surgical techniques for pediatric cataract surgery practiced in the institute.^[14] In brief, it consisted of lens aspiration, primary posterior capsulotomy, anterior vitrectomy, and posterior chamber intraocular lens (PCIOL) implantation through a clear corneal incision and securing the wound with 10-0 nylon sutures.

PCIOL was implanted in children with age-appropriate axial length (at least 19.0 mm in the first year of life and for older children axial length appropriate for age)^[15] and minimum corneal (horizontal white to white) diameter ≥ 10.5 mm, no associated anterior segment dysgenesis, and normal intraocular pressure (IOP).^[16] The Sanders–Retzlaff–Kraff II (SRK II) formula was used for IOL power calculation in all children (based on our prior experience giving the least prediction error with SRK II formula).^[17] The undercorrection of IOL power was done according to the published guidelines.^[18]

The choice of IOLs was single or three-piece hydrophobic acrylic (Alcon-Acrysof SA60AT, Acrysof MA60AC) or preloaded single-piece hydrophobic acrylic (AuroLab-Aurovue EVHP760AP). Single-piece hydrophobic acrylic lenses were chosen for in-the-bag implantation, and three-piece lenses were chosen if sulcus implantation was performed.

Postoperatively, all patients were prescribed topical tobramycin 0.3% eye drops 4 times a day for a week, topical prednisolone acetate 1% eye drops 8–12 times a day, gradually tapered over 6 weeks, and topical atropine sulfate 1% (for children under 2 years)/homatropine bromide 2% eye drop (for children ≥ 2 years) twice a day for 2 weeks. Examination under anesthesia was performed to remove the sutures and prescribe the suitable glass after 1–2 weeks of cataract surgery. All children were scheduled for review on day 1, weeks 1–2, and weeks 6–8, and the parents were counseled accordingly.

At each follow-up visit, visual acuity assessment with age-appropriate methods, retinoscopy, slit-lamp examination, and IOP measurement (Perkins tonometer, Clement Clarke International, or I-care tonometer (Icare® TA01i)) were done. Teller acuity cards, Lea symbols, Kay picture charts, or Snellen charts were used for visual acuity assessment and then converted to LogMAR scale. Glaucoma was diagnosed with IOP > 22 mmHg and progressive optic nerve cupping more than 0.2 from the baseline with or without myopic shift.^[18]

Statistical analysis: The data were entered in Microsoft Excel (Microsoft Inc., Richmond, USA) spreadsheet and analyzed using IBM-Statistical Package for Social Sciences (SPSS) version 21.0 (Armonk, NY: IBM Corp).

Categorical variables were presented in number and percentage (%), and continuous variables were presented as means with standard deviations and median with interquartile range (IQR). The Shapiro–Wilk test tested the normality of data. Univariate and multivariate linear regression was performed to determine factors affecting corrected distance visual acuity at a 6-week follow-up. We compared clinical features and visual outcomes among children with congenital and developmental cataracts. A *P* value of < 0.05 was considered statistically significant.

Results

Demographic features: During this period, 352 children from 9 tribal districts, operated for cataract at the institute, were analyzed. The tribal population in eight of nine districts (Gajapati, Kandhamal, Kendujhar, Koraput, Malkangiri, Mayurbhanj, Nabarangpur, Rayagada, Sundergarh) was above 50%, and only one district had a population of 45% as per the 2011 census [supplement Fig. 1]. These districts are 200–600 km away from the tertiary eye care center. The mean presenting age was 9.11 ± 4.4 years; 151 tribal children (43%) presented after 10 years of age, and 133 (38%) were females.

Clinical features: In this cohort of 352 children (536 eyes with cataract), 225 children (64%) had congenital cataract, and 127 (36%) had developmental cataract. In the congenital cataract group, 40 (11%) had a family history of childhood cataract, and in the developmental group, 59 (17%) had idiopathic cataract. Two hundred and thirty-five eyes (44%) had total white cataract, and 205 eyes (37%) had lamellar

cataract. Cataract was bilateral in 205 children (58%). The most common presenting complaint was decreased vision (71%; $n = 251$). One-third of children ($n = 113$; 32%) had associated strabismus, and 57 (16%) had associated nystagmus [Table 1]. Median best-corrected visual acuity (BCVA) was 1 LogMAR (IQR, 0.1–2) (Snellen equivalent, 20/250). Mean BCVA was 1.11 ± 1 LogMAR. IOL insertion was deferred in 26% ($n = 94$ eyes) children due to a small horizontal corneal diameter and contracted calcified/unstable bag.

Visual outcomes and follow-up: In this study, 55% ($n = 194$) children completed a 6-week follow-up, and 17% ($n = 61$) children completed a 3-month follow-up. The proportion of children retuning for a 6-week review reduced from 62.4% (300 km distance) to 54.4% (301–500 km) to 33.3% (over 501 km). At 6-week follow-up, the median BCVA was 0.8 LogMAR (IQR, 0.2–2) (Snellen equivalent 20/32). Mean BCVA was 1.02 ± 1.11 LogMAR. Children with congenital cataract had worse visual outcomes (median BCVA: 20/320; 1.25 LogMAR; IQR, 0.3–2 LogMAR). Mean BCVA in children with congenital cataract was 1.17 ± 1.25 LogMAR. In contrast, in children with developmental cataract, the median Snellen BCVA was 20/50 (0.4, LogMAR, IQR: 0.2–2). In this group, the mean BCVA was 0.74 ± 0.73 LogMAR. This difference was statistically significant ($P = 0.001$) [E-supplement Table 1]. At a 6-week follow-up, the BCVA was $\geq 20/60$ in 124 children (13%) with congenital cataract and 70 children (54%) with developmental cataract ($P < 0.0001$). The median spherical equivalent r at 6 weeks was $+1.5$ D (IQR, 0–6) with a mean value of 3.81 D ± 6.2 .

Univariate linear regression analysis showed that age at presentation, presenting vision, bilaterality, presentation with a visible white spot at the pupillary area (suggestive of total cataract), congenital cataract, coexisting strabismus, and nystagmus significantly influenced 6-week BCVA [Table 2]. On multivariate linear regression analysis, the age at presentation ($P = 0.020$), worse BCVA at

presentation ($P < 0.0001$), congenital cataracts ($P = 0.001$), and presence of nystagmus ($P = 0.005$) were responsible for worse visual outcome [Table 3].

Discussion

Our study presents the data from the tribal children undergoing cataract surgery in East India. Our literature search (PubMed search, Google scholar) showed only one report from West India.^[12]

Odisha (East India) is home to 9.7% of India's tribal population (third after Indian states of Madhya Pradesh and Maharashtra), and 22.8% population of Odisha is tribal.^[19] It exceeded 50% of the total population in 8 of 30 districts of the state. In this cohort, the children with pediatric cataract were from these eight districts, and the tribal people in the ninth district were 45.2% (Kendujhar, Census 2011). In general, the health indices in India's tribal population are behind the nontribal population,^[20] so also the health-seeking behavior for eye care.^[21,22] As per a study from central rural India, the delay in surgery in rural population is multifactorial which includes unawareness, misdiagnosis, self-treatment, cost, distance from the hospital, and poor socioeconomic status.^[23] In this context, it was not surprising that the children with cataract presented at an age older than even the children from rural India (mean 4.4–7.0 years vs. mean 9 years in this study)^[23,24] and 45% children did not return for the sixth-week review.

Our study found that only 28% of children achieved BCVA $\geq 20/60$, and it was corroborating with the previously published reports ranging from 19% to 36%.^[24–26] It is a matter of concern. Good outcome after cataract surgery in children partly depends on surgery (earlier the better), laterality of affection (bilateral cataract is better than unilateral cataract), and postoperative rehabilitation, including refraction, and amblyopia therapy.^[27] Other predictors are the absence of comorbidities such as nystagmus and strabismus and surgery with IOL implantation. In our cohort, 32% of eyes had strabismus, 16% had nystagmus, and IOL was not implanted in one-fourth of children. 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.

Two factors impacted the regularity of postoperative review in our study: the program support and the surgical center's distance.^[28] Surgery for these children was financed by the RBSK (*Rashtriya Bal Swasthya Karyakram*, National children Health Program), a public health program in India.^[29] While the RBSK is responsible for disease detection and treatment, including surgery, the program does not directly arrange for postoperative reviews. The mean distance of these nine districts in this cohort was 373 km (200–614 km) [Table 4] [Supplementary Fig. 1]. In the final analysis, the proportion of children retuning for a 6-week review reduced from 62.4% (300 km distance) to 54.4% (301–500 km) to 33.3% (over 501 km) [Table 4]. This difference was significant among all the three groups ($P < 0.008$). An individual comparison (Chi-square test) showed that this difference in follow-up rates was statistically significant between groups 1 and 3 ($P = 0.002$) and groups 2 and 3 ($P = 0.048$). However, study from South India

Table 1: Clinical features of childhood cataract in tribal children

Parameters at presentation	352 children; 536 cataracts n (%)
Cataract morphology	
Total white	235 (44)
Lamellar	205 (37)
Bilateral	205 (58)
Association	
Strabismus	113 (32.1)
Nystagmus	57 (16.2)
Poor fixation	21 (6.0)
Chief complaint	
Reduced visual acuity	253 (71.3)
White opacity in eye	97 (27.3)
Strabismus	2 (0.3)
Presenting vision	
$\geq 20/200$	82 (15.3)
<20/200 to counting finger at 1 m	61 (17)
<Counting finger at 1 m	275 (51.3)
Fixing and following light	118 (22)

Table 2: Univariate linear regression analysis shows effect of factors affecting best-corrected visual acuity (BCVA) at 6-week follow-up

Variable	Beta coefficient	Standard error	P	Lower bound (95%)	Upper bound (95%)	F ²
Age at presentation (years)	0.022	0.011	0.043	0.001	0.043	1.44
Female gender	0.086	0.098	0.381	-0.107	0.278	0.27
Unilateral presentation	-0.413	0.106	0.0001	-0.621	-0.204	5.08
Corrected distance visual acuity at presentation	0.281	0.044	<0.0001	0.194	0.368	13.31
Type of cataract						3.49
Congenital cataract	-0.3152	-0.098	0.002	-0.509	-0.122	
Presenting complaint						3.02
White spot	0.272	0.102	0.008	0.071	0.473	
Strabismus	0.208	0.564	0.713	-0.903	1.318	
Second opinion	-0.892	0.796	0.263	-2.459	0.674	
Poor fixation behavior	0.020	0.201	0.921	-0.375	0.415	
Nystagmus	0.318	0.124	0.011	0.073	0.563	2.25
Strabismus	0.397	0.100	<0.0001	0.201	0.594	5.29
Type of cataract						8.35
Zonular cataract	-1.050	0.869	0.228	-2.761	0.661	
Total cataract	-0.860	0.780	0.271	-2.396	0.676	
Lamellar	-1.225	0.781	0.118	-2.762	0.313	
Posterior polar cataract	-0.900	0.952	0.345	-2.774	0.974	
Cortical	-1.800	0.952	0.060	-3.674	0.074	
Absorbed	-0.833	0.789	0.292	-2.386	0.720	
Nuclear	-0.900	0.851	0.291	-2.576	0.776	

This table shows a younger age at presentation (congenital cataract), unilateral cataract, visual acuity at presentation, associated nystagmus, and strabismus led to worse final visual outcome at 6 weeks

Table 3: Multivariate linear regression analysis shows the effect of factors affecting best-corrected visual acuity (BCVA) at 6-week follow-up

Variable	Beta coefficient	Standard error	P	Lower bound (95%)	Upper bound (95%)	F ²
Age at presentation (years)	0.028	0.013	0.036	0.002	0.054	3.49
Best-corrected visual acuity at presentation	0.206	0.046	<0.0001	0.115	0.297	
Unilateral presentation	-0.247	0.127	0.052	-0.497	0.002	
Type of cataract						
Congenital cataract	-0.380	0.109	0.001	-0.594	-0.165	
Presenting complaint						
White spot	0.184	0.112	0.102	-0.037	0.406	
Strabismus	0.644	0.519	0.216	-0.379	1.666	
Second opinion	-0.857	0.711	0.229	-2.258	0.544	
White spot, strabismus	0.155	0.805	0.847	-1.431	1.741	
Nystagmus	0.250	0.124	0.045	0.005	0.496	
Strabismus	0.146	0.102	0.155	-0.056	0.348	
Lens findings						
Zonular cataract	-0.666	0.785	0.397	-2.212	0.880	
Total cataract	-0.561	0.710	0.430	-1.960	0.838	
Lamellar	-0.718	0.713	0.315	-2.123	0.687	
Posterior polar cataract	-0.950	0.852	0.266	-2.628	0.729	
Cortical	-1.186	0.874	0.176	-2.907	0.535	
Absorbed	-0.622	0.714	0.384	-2.027	0.783	
Nuclear	-1.089	0.822	0.186	-2.708	0.530	

This table shows a younger age at presentation (congenital cataract), unilateral cataract, worse visual acuity at presentation, associated nystagmus, and strabismus affected the final visual outcome at 6 weeks

Table 4: Distribution of the percentage and distance of tribal districts from “tertiary eye care center” along with 6-week and 3-month follow-up rates

Distance from tertiary eye care center (km)	Districts (% tribal population)	Total children	6-week Review number (%)	3-month Review number (%)	P
Group 1 200-300	Gajapati (54.3) Kandhamal (53.6) Kendujhar (45.2) Mayurbhanj (58.7)	157	98 (62.4)	33 (21)	0.0081
Group 2 300-500	Koraput (50.6) Rayagada (56.0) Sundergarh (50.7)	136	74 (54.4)	25 (18.3)	
Group 3 >501	Malkangiri (57.8) Nabrangpur (55.8)	59	23 (39)	1 (1.6)	

As we can observe in this table, as the distance of the tribal district from the tertiary eye care increased beyond 300 km, 6-week and 3-month follow-up rates decreased significantly. The difference in percentage of children who came for 6-week follow-up was statistically significant across all distance categories. An individual comparison with the Chi-square test showed this difference in follow-up rates and was statistically significant between groups 1 and 3 ($P=0.002$) and groups 2 and 3 ($P=0.0478$).

by Chougule *et al.* has suggested that age at surgery and low socioeconomic status are the most important factors associated with poor follow-up.^[30] The poor outcome in our cohort could be due to delayed presentation (43%, $n = -151$), amblyopia due to the unilateral nature of cataract (42%, $n = 147$), and other comorbid factors like strabismus 32%, nystagmus 16%, and surgical aphakia 27% ($n = 147$). We believe that timely follow-up and appropriate interventions could have addressed a few of these, such as coexisting amblyopia (primarily deprivational but possibly also strabismic and anisometropic amblyopia in aphakia) by appropriate refractive correction and early institution of amblyopia therapy.

The impact of the tribal location was not considered since the tribal population was nearly similar. Besides, the low rate of literacy, lack of awareness, and current knowledge-attitude practices in the tribal community of the Odisha state in India could have also contributed to the parents' health-seeking behavior.

We propose that provision of adequate care closer to residence might help in this tribal population. The state of Odisha has district-level hospitals in all these districts but does not have comprehensive eye care programs, including surgery for cataract under general anesthesia. It would take some time to develop the required infrastructure and human resources for health. In the interim time, we will recommend modifying health financing to support these children up to 3 months of postoperative care for all eye surgeries, including cataract. Further, training of health personnel in providing basic postoperative care at the district level, such as VA assessment, refraction, amblyopia therapy, low vision services, rehabilitation, and early referral where needed, would help in improving visual outcomes in these children. Their training in early detection of congenital cataracts by identifying poor visual behavior, white reflex in the eye, sometimes associated nystagmus, and strabismus can be augmented. These practices can help to improve the visual outcome of pediatric cataract in the tribal population.

We acknowledge the following limitations of the study: retrospective data analysis, inadequate follow-up visits, lack of laboratory testing to establish the etiology of cataract, and insufficient socioeconomic information from the family. Due to retrospective nature of the study, we observed wide

variations in the age at presentation and we could draw meaningful comparisons only in the subgroups for infantile and developmental cataracts. However, this difference is important as the visual prognosis is really different in the children operated in infancy and later on. Despite these limitations, this is the first such report on pediatric cataracts from Odisha's tribal community (India). This report's information could be used for health policy planning in the predominantly tribal population of Odisha. These learnings can be further applied in other similar ecosystems in India.

Conclusion

Children from the tribal community with cataract present late with poor presenting VA and have suboptimal follow-up and visual outcomes. Robust advocacy, delivery of care closer to the place of residence, and logistic support for follow-up care could improve early detection, quality of postoperative care and outcomes.

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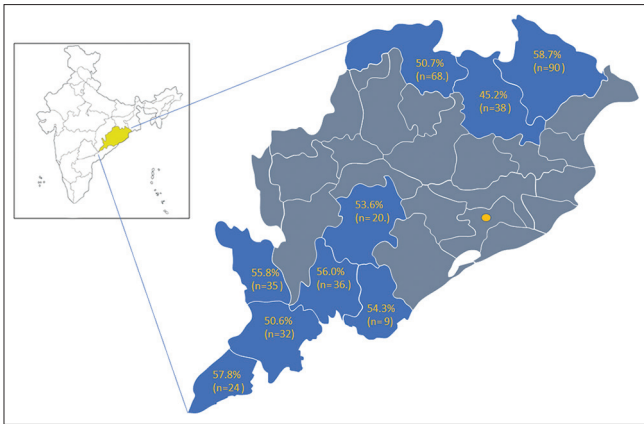
Conflicts of interest

There are no conflicts of interest.

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Supplement Figure 1: Showing the distribution of various tribal districts, percentage of their tribal populations, and number of children from each tribal district. It shows that all children belonged to one of the nine tribal districts. Source: Figure has been taken from public domain map. India internet site: deconstructed

E-supplement Table 1: Comparison of best-corrected visual acuity (BCVA) at presentation, 6-week, and 3-month follow-up visit among children with congenital and developmental cataract

LogMAR BCVA	Congenital cataract	Developmental cataract	<i>P</i>
At presentation			
Median (IQR)	1.1 (0-2)	0.8 (0.4-2)	0.44*
6-week Postoperative follow-up			
Median (IQR)	1.25 (0.3-2)	0.4 (0.2-1.2)	0.001
3-month Postoperative follow-up			
Median (IQR)	1 (0.2-1.55)	0.3 (0.1-0.6)	0.03

*Comparison for median visual acuity done among children with congenital and developmental cataract using Mann-Whitney *U* test