

## Perspectives and impediment to eye care in caregivers of children with childhood glaucoma

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**Purpose:** To study the perceptions, attitude, knowledge of the disease, and impediments to seeking early eye care in caregivers of children with childhood glaucoma. **Methods:** The study included new and old children diagnosed with childhood glaucoma (which included congenital glaucoma and developmental glaucoma) at a tertiary hospital of east India. The caregivers were administered a video-based questionnaire through open-ended questions intended to collect demographic and other personal details such as caregiver's socioeconomic status, knowledge, attitude towards eye health, and other social barriers. The responses were analyzed using thematic analysis technique into different buckets such as social status, knowledge/attitude, and sociocultural beliefs while individual responses in each bucket were analyzed. **Results:** Of a total of 43 patients included, >75% of patients came from places >200 km from the eye care centre with >50% coming from >300 km. Most patients presented either <1 year (42%,  $n = 18$ ) or >3 years (52%,  $n = 22$ ) with only 2% ( $n = 3$ ) presenting between 1–3 years of age. The mother was the first person of contact to diagnose the eye abnormality in >45% of patients. Comparing differences among children who presented within 1 year of first diagnosis and those that presented later, caregivers sailing from long-distance >200 km from an eye care center, monthly income <5000 INR, and those with social/cultural taboos (like children's eyes should not be operated) were more likely to seek delayed eye care for congenital glaucoma,  $P < 0.001$ . **Conclusion:** Impediments in seeking early eye care for blinding diseases in children (including distance from the nearest hospital, low socioeconomic constraints, and sociocultural beliefs/taboo) mandate serious policies towards improving education about eye disease and eye health among caregivers.

**Key words:** Awareness, blindness, caregivers, childhood glaucoma, perspectives and knowledge

Congenital glaucoma (CG) represents a developmental deformity of the angle structures including the trabecular meshwork causing impaired aqueous drainage and raised intraocular pressure (IOP) and glaucomatous optic nerve head (ONH) cupping.<sup>[1,2]</sup> Majority of cases usually present at birth or within the first year of life are recognized typically by the triad of epiphora, photophobia, and enlargement of the cornea and globe.<sup>[1]</sup> Prompt recognition and surgery can reduce the IOP and help in reversing ONH cupping and function in children and infants owing to the elasticity of the lamina cribrosa.<sup>[3-6]</sup> A large number of studies lend credence to the benefits of early surgical intervention in these patients with untreated/delayed treatment often leading to blindness and poor visual outcomes.<sup>[5-8]</sup>

The overall outcome of these patients in developing countries remains poor with delayed presentation or delay in seeking definitive treatment.<sup>[3,7,9-14]</sup> This is compounded by poor literacy rates and poor awareness among caregivers and parents of children apart from social stigmas or cultural beliefs. Majority of patients (about 60%) are diagnosed by the age of 6 months and 80% are diagnosed within the first year

of life.<sup>[1,2]</sup> Since laminar deformity and glaucomatous damage are mostly reversible in children with early surgery, prompt and early recognition of the disease is crucial for maintaining useful vision in these children while delayed diagnosis or treatment gives very poor outcomes owing to corneal opacity, amblyopia, and irreversible disc damage.<sup>[7,8]</sup> Several studies and questionnaire-based surveys have highlighted the burden on caregivers of children with pediatric diseases,<sup>[9-14]</sup> yet, these have not reduced the incidence of these disease in developing countries where overall awareness and acceptance of early treatment still remains poor even in literate patients.<sup>[1,2]</sup> Social causes and impediments of the caregivers, as well as other factors in a real-life scenario, can give a perspective of the actual causes for such delayed diagnosis apart from low awareness or acceptance to medical or surgical treatments for such diseases in children.<sup>[8,9,11]</sup> Insights into all the possible causes for delay in seeking early eye care for each caregiver in a specific setting can help understand the myriad reasons for the delayed presentation which can help formulate steps for policymakers and clinicians.

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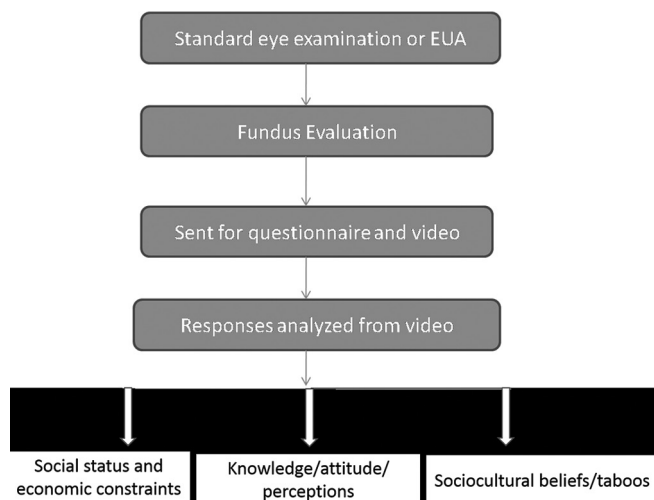
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## Methods

The study population included new and old children diagnosed with childhood glaucoma (which included congenital glaucoma and developmental glaucoma) at the glaucoma service of tertiary eye centre from 2015 January to 2016 December. Congenital glaucoma was diagnosed in the presence of enlarged corneal diameter with axial enlargement of the globe (buphthalmos), raised intraocular pressure (IOP), and optic disc changes with or without other signs such as Haab striae, limbal stretching, and corneal edema noted from birth till 3 years (findings documented under physiological sleep or under examination under anesthesia) while developmental glaucoma was diagnosed in the presence of raised IOP, disc damage, and other associated ocular findings noted at any age without syndromic associations. This study adhered to the tenets of the Declaration of Helsinki and was approved by the institutional review board. Children were only included if the parents consented for interviewing and inclusion in the study. All patients (primary or referred) with primary glaucoma (congenital or developmental) attending the glaucoma service for management had their initial ophthalmological workup, including history, visual acuity, refraction, and intraocular pressure by Perkins tonometer and gonioscopy either under physiological sleep or under anesthesia (if corneal clarity permits).

After the standard and initial eye examination of the child, the caregivers were sent to an optometrist for questionnaire through video. The interview was intended to collect details such as parent’s education background, occupation, residence from the hospital, caregiver’s monthly income, knowledge, attitude towards eye health, and other social barriers, Fig. 1. All questions were administered in an open-ended fashion by the same optometrist blinded to the other clinical details of the patient [Supplemental Video S1]. The questions were all administered in the local language that the patient understood and was administered to both parents. Any parent not willing to answer any question was given the choice to exit from the study and the patient was excluded. All video-based questionnaires were administered in a nonlinear or nonstructured fashion however, covering all aspects such as education, income, social



**Figure 1:** The flowchart showing the flow of patients for administering a video-based questionnaire to caregivers of children with childhood glaucoma

status, and other details. This ensured that the actual reason/s the parent or caregivers come forth with rather than leading questions based on known or expected reasons for delayed presentation. If caregivers were unable to give pertinent and reliable history regarding the eye condition or were unaware of details of the child (for example, the income of parent’s history from caregivers of children belonging to orphanages), to those patients were excluded.

### Video analysis

Each video was analyzed by a person blinded to other clinical or demographic details of the patient. In the first step, transcriptions were analyzed by thematic analysis wherein sections of the data responses in each video were clustered into different buckets or categories. These were further elaborated into individual themes or concepts of each response category. The responses to the questions were then analyzed to assess possible factors for late presentation or access to healthcare service or other impediments to accessing healthcare early in the disease process.

### Statistics

All statistical analyses were performed using Stata Corp (Version 10.0, USA) with alpha error set at  $P < 0.05$ . Descriptive statistics are represented as mean ( $\pm$  SD) for parametric data or median ( $\pm$  Interquartile range) for non-parametric data. Differences between groups were analyzed using Student “t- test” for linear variables or Chi-square test for categorical variables. Multiple logistic regression with odds ratio was analyzed to evaluate factors influencing the delayed presentation or seeking eye care.

## Results

Of 48 children with congenital glaucoma, 5 children brought from orphanages or other attendants, were excluded owing to nonavailability of proper history of the disease or any other details of the patient. A total of 43 patients were finally included in the study, comprising of mostly male children hailing from places in and around 200 km from the hospital, Table 1. Most patients were from Ganjam district comprising 35–40% of the total cohort, Fig. 2. More than 75% patients came from places >200 km from the eye care center with >50% coming from >300 km and only 10% of the total coming from within 100 km of the institute, Table 2.

**Table 1: Clinical characteristics of patients with childhood glaucoma**

Variables	Mean ( $\pm$ SD) or median ( $\pm$ IQR) or n, %
Mean age (years)	5.98 $\pm$ 0.95
Mean follow-up at the hospital (days)	240 $\pm$ 40.96
Number of medications at presentation	0.56 $\pm$ 0.15
Cup-disc ratio at presentation	0.54 $\pm$ 0.05
Diagnosis (n, (%))	
Infantile Glaucoma	18 (41%)
Congenital glaucoma	20 (46%)
Developmental glaucoma	05 (13%)
History of Consanguinity (n, (%))	16 (37%)
The time lag from diagnosis to presentation at the hospital (days)	354 (0-3470)



**Figure 2:** The map of the state of Odisha in east India which comprises of several districts with a proportion of place of origin of study patients with childhood glaucoma as shown

**Table 2: The distance to be travelled by caregivers of congenital glaucoma to seek eye care at the tertiary eye care center**

Distance to Hospital (km)	Percentage of caregivers
50-100	10%
100-200	10%
200-300	16%
300-400	36%
400-500	21%
500-600	7%

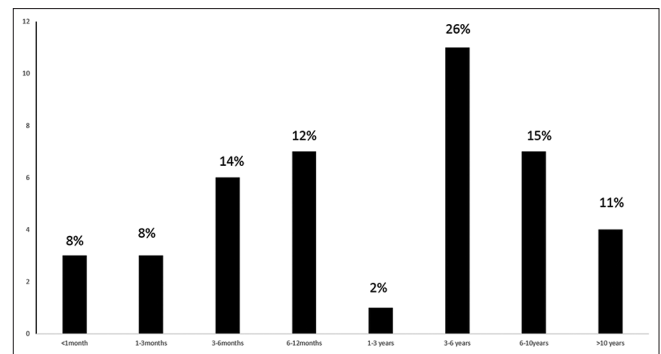
The age at presentation surprisingly showed a biphasic pattern with most patients presenting either <1 year or >3 years with only 2% presenting between 1–3 years of age, Fig. 3. The primary contact who diagnosed/noticed eye abnormality first was the mother in 45% cases with school teachers noticing it in 18% cases. Only 2–4% of patients were diagnosed to have an eye abnormality by health workers/professionals.

**Elaboration of specific themes and concepts**

*Social status and economic constraints of caregivers*

Fathers of the children included had varying levels of education with 50% having completed education up to 12<sup>th</sup> standard while the rest were educated to 10<sup>th</sup> standard or below, Fig. 4. Most fathers were daily wage laborers or farmers comprising >50% with surprisingly 2–5% also being professional workers like pharmacists, businessman, or government officials. The mothers of the children included were mostly housewives (66%) with none of them being educated beyond 5<sup>th</sup> grade or active in any daily work. The monthly income of the parents/caregivers ranged from 5000–7000 Indian rupees per month with only 10% having a monthly salary of 16000 INR or more. It is worth remembering that this monthly income is an average estimate since the income of daily laborers would be variable each month depending upon daily availability of work.

Poor socioeconomic status as serious impediments to seeking eye care services is reflected by some responses like



**Figure 3:** Distribution of age at presentation to a tertiary hospital for children with childhood glaucoma in the state of Odisha, India

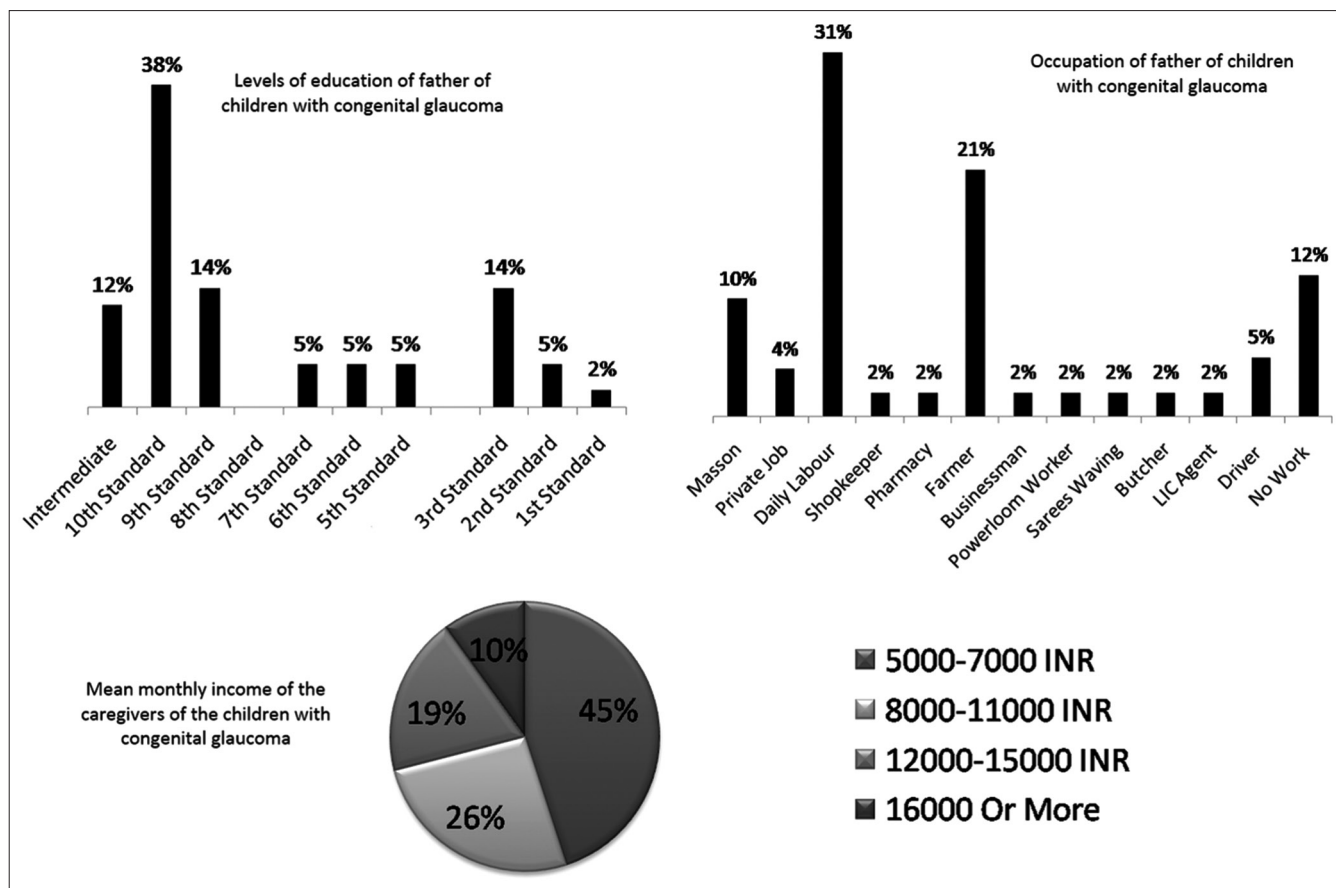
“We did not know how to go to the hospital”, “we did not have money to go to the hospital to which we were directed” or “we didn’t know where the hospital is located”. This is combined with poor prioritization as effected in sentences like “we could not go to hospital because we’re busy with work” or we do not get time off our daily work to bring our child to the hospital” or “father has to work daily and so cannot take me or the child to the hospital”, Table 3.

*Knowledge, attitude/perception in caregivers*

Assessing the awareness about the eye condition, 28% of the parents did not have any idea about the eye abnormality, namely, congenital glaucoma, while 19% of caregivers thought that the child was too young to be treated medically/ surgically. Around 17% of parents also thought that God would take care of their child and its disease, while 14% thought that this disease only affects adults. Only 12% of cases, parents could not find their way to any eye care center owing to lack of proper guidance or directions. Around 26% of parents did not care about the eye health of the child thinking it is too much laborious and difficult for them to take care of the eye condition, 19% thought that eye would become normal as the child grows, and 19% thought that this condition is incurable and cannot be treated medically or surgically. Importantly, 14% of mothers stated that the fathers of the children did not care for the child’s condition which caused a delay in seeking eye care despite noticing an abnormality early at age. Some glaring examples of the poor awareness among the caregivers are reflected by the following-“we thought that the treatment is costly”, we did not know that this can be treated or we were told that there is no cure for this condition”, Table 3.

*Sociocultural beliefs/taboo in caregivers*

Looking at social barriers to seeking early eye care, 22% said that neighbors advised the parents against visiting a hospital for seeking early eye care, 16% sought delayed eye care for fear of expenses involved in eye care, 15% of parents were busy working for daily essentials such as food and shelter leaving no time for specialized and additional requirements like eye care, 14% were advised by a local general physician against any intervention at the age of presentation, and to seek eye care only when the child grows older. In 11% of cases, the father was residing outside which caused delayed treatment despite early detection of an abnormality and another 11% presented late because the grandparents/elders refused to seek any medical aid for the eye condition at any hospital. Examples



**Figure 4:** The social status as reflected by the education levels (as per Indian system of education) of the father, the occupation of the father, and average estimated monthly income in Indian rupees (INR)

**Table 3: Interview quotations relevant to knowledge, attitude, and various social barriers associated with delayed presentation**

Focal Points	Emerging Themes	Interview Quotations
Poor socioeconomic status	"No idea about eye diseases". Could not find a way to reach the hospital. Fear of the cost of medical care Busy at completing daily chores and earning a livelihood.	"We live in villages where there is nobody who knows the eye problem". "My husband resides outside; I do not know the way to the hospital," says the mother of the child. "We thought that our child's eye will become normal as the child grows and becomes young". "We didn't have money to go to the hospital to which we were directed" "We are too busy earning our daily food and do not have money or time for medical care for our child which would be costly" "We thought that this large hospital set up would be demanding more fees treating our child- we cannot afford that much". "We both are busy at collecting for food to eat-how could we raise fund to meet the hospital expenditure, travel expenses, hospital stay"
Attitude/perception	Father's carelessness and hesitation Unaware that this condition if untreated causes blindness. Eye not part of general health	Father says "I don't think my baby has any serious eye problems requiring immediate care at this age" Father says "I would not take my child to any hospital for treatment at this age-this would automatically go away". "We thought that eye diseases only affect adults". "Overall, the health of the child was good and we know that those who have good health, have good eyes-so our child is also OK".
Sociocultural beliefs/taboo	Neighbors/elders advise against any eye care due to social taboos/beliefs Sociocultural belief systems Previous doctor/ pediatrician/local practitioner delaying eye care.	Our villagers/grandfather has said that the child has no serious eye problem requiring any treatment. "Our elders say that our child has large eyes and such large eyes are a sign of good luck and beautiful eyes". "God will take care of the child's eye", children should not be operated" "When we took the child to the doctor, he said the treatment is possible and should be sought only after the child is 4-5 years old".



of the fatalistic beliefs that caregivers had regarding the child's condition are given below-

"God will take care of the child's eye", the large eyes are God's gift for beautiful eyes for our child, "this condition does not affect children

Or we thought this is not curable", we thought that "children should not be operated "or "we will not subject our child to surgery now and would wait until he grows", family elders advised us against any surgery" and "we thought that this will become OK as the child grows".

Comparing differences among children who presented within 1 year of first diagnosis and those that presented later, caregivers hailing from long-distance >200 km from an eye care center, monthly income <5000 INR, and those with social/cultural taboos were more likely to seek delayed eye care for congenital glaucoma,  $P < 0.001$ , Tables 4 and 5.

## Discussion

Childhood glaucoma in developing countries like India poses a challenge to the health system owing to clinical challenges and poor surgical outcomes.<sup>[3,7,8,10,11,14]</sup> This is further compounded by a lack of awareness among clinicians, the general public, and caregivers about the disease.<sup>[10,11]</sup>

Unlike adult glaucoma which is largely symptomatic leading to delayed presentation, childhood glaucoma is marked by early appearance of signs and evident symptoms.<sup>[1,2]</sup> This study found significant barriers to seeking early eye care in caregivers of childhood glaucoma which included the distance from the nearest eye care center, low monthly income, sociocultural taboos, and belief systems ingrained in the society regarding the disease or surgery as a remedial measure in children. These results support the existing limited body of evidence for barriers to seeking eye care services or adherence to medications in adult glaucoma and suggest that presence of typical and early symptoms is not enough for early presentation to the clinic in childhood glaucoma with similar barriers. Clearly, early onset of symptoms was not useful in prompting parents or caregivers to seek early eye care in children where social taboos and beliefs were the predominant deterrent and barriers in this cohort. While early surgery can reverse the glaucomatous cupping and restore optic nerve function in children, these barriers in developing countries result in delayed presentation and associated comorbidities which account for consequent poor overall surgical outcome in these cases. This study also brought forth insights into the actual reasons faced by the caregivers or parents of the children. This was made possible because of the design of the study

which did not include QOL based questionnaires. This ensured comparison of these real-life reasons and situations faced by parents or caregivers without introducing bias incorporation due to the inclusion of known or expected causes rather than actual causes for delayed presentation to eye care services. The clinical significance, therefore, is for every clinician to get an insight into the real-life problems and apprehensions of the caregivers of children presenting to them or give us an insight into social taboos existing in the society.

Access to eye care is often the most common qualitative barrier to early eye care for the majority of eye abnormalities including cataract and glaucoma.<sup>[10,11,14,15-20]</sup> Poor monthly income, especially in daily wage laborers, forming majority of the cohort in this study, was an important cause for inability to access eye care. Financial constraints or lack of awareness have been reported to be significant barriers for successful eye health programs in developing countries.<sup>[14,17-20]</sup> Yet, it is surprising that children with evident symptoms are denied even a basic eye examination owing to such poor wages of parents or simply the lack of time/prioritization over daily mundane tasks for the caregivers in developing countries.

Often, issues like cultural and regional practices like consanguinity may influence disease patterns and morbidities for a hereditary disease like glaucoma in that population.<sup>[1,2]</sup> The geographic area of Odisha includes 30 districts of which 35-40% of patients came from Ganjam district which comprises the south-east part of Odisha. This area is marked by high rates of consanguineous marriage being a routine cultural norm with little knowledge of the risks of hereditary diseases in the population resulting from consanguinity. Education of the general public regarding risks of consanguinity by policymakers, availability of parental counseling for children with genetic diseases in urban and rural areas and active participation in dissemination of this knowledge among patients and community by health officials provides a potential area for further research and could be an effective tool to reduce the disease burden of childhood glaucoma.

Though the burden of having a child with glaucoma with easily evident and recognizable signs of poor vision is high, recognition in such instances is rarely the first step towards a cure or treatment, owing to social, economic, or cultural constraints.<sup>[9,10,11,14,15,20-23]</sup> The primary contact as expected was the mother who was the first to notice eye abnormality in 45% cases while school teachers noticed the eye condition in only 18% cases. It was worth noticing that mothers explained about the lack of cooperation from the husband or family elders despite noticing the eye abnormality early. An earlier study about the knowledge and awareness of new born

**Table 4: Characteristics of patients with congenital glaucoma associated with a delayed presentation at the tertiary care hospital**

Parameters	<1 year n=18	>3 year n=25	P
Distance of caregiver's home from hospital ≤ 50 km	14 (77%)	1 (4%)	<0.001
Monthly Income ≤ 5000 INR	6 (33%)	22 (92%)	<0.001
History of Consanguinity	4	8	0.04
Time lag from diagnosis to presentation at the hospital (days)	76 (0-211)	547 (245-3470)	0.001
Poor knowledge about the disease	5 (28%)	21 (88%)	P<0.001
Sociocultural taboos towards eye care/health	3 (16%)	22 (92%)	P<0.001

**Table 5: Analysis of factors associated with delayed presentation of congenital glaucoma**

Parameters	Odds ratio	95% CI	P
Distance (>200 km)	80.5	8.153-794.7	<0.0001
Monthly Income <5,000 INR	22	3.830-126.3	<0.0001
Poor knowledge of disease	18.2	3.712-89.22	<0.0001
Sociocultural taboos towards eye care/health	38.5	6.207-238.7	<0.0001

screening test among Saudi women were found to be low.<sup>[11]</sup> A mother's education may contribute to both early diagnosis and accountability of decision making in any household which is often minimized in a patriarchal or male-dominant cultural society. This is more often seen in developing countries where most women are uneducated or are housewives who are not empowered with decision making powers at home. Hence, women empowerment in decision making and educating the mother regarding the diagnosis of childhood disorders may lead to an improvement in child health and improve the success of any healthcare system. The education status of the fathers of the children in this cohort revealed that 50% had completed education up to 12<sup>th</sup> standard/class (as per Indian education system) with the rest being educated to different levels. Even after acquiring so much education, they were unaware and their knowledge was limited regarding eye health. Most fathers were daily wage laborers or farmers comprising >50%, who are generally busy at collecting means for their daily livelihood. In Odisha, laborers and farmers find their jobs during day hours that do not permit them to attend the hospital with their child. However, surprisingly some were also professional workers like pharmacists and businessman who may be logically expected to be active in seeking eye care early. These results force us to introspect the actual value of education and awareness/beliefs of eye diseases affecting children among the general public. Most caregivers thought that this does not affect children or relied on destiny or God to cure the condition while most thought that children are too small to undergo any medical/surgical treatment. This also calls for revolutionary health education programs and formulation of stronger policies directed towards educating the public about the "curability" of eye conditions when diagnosed early.

This study was restricted to patients attending a single referral tertiary eye care center in east India and the results though in concordance with earlier studies cannot reflect the patterns in a larger population or other countries across the globe. We did not account for those children who were seen at the hospital but could not be included owing to nonconsenting parents. Also, we did not probe deep into deeper reasons for social beliefs and taboos like cultural norms and other social ethics prevalent in that population. These can be very region-specific and therefore may impact the results and belief systems in different populations in different countries.

## Conclusion

This study highlights impending large gaps in eye care for children with childhood glaucoma and force us to implement strong policies and reforms intended to bridge the lacuna of knowledge and awareness among caregivers. Improvement of the overall socioeconomic status combined with a parallel

improvement in education about eye disease among children is quintessential for ensuring early diagnosis and timely eye care for successful eye health programs in children.

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## Conflicts of interest

There are no conflicts of interest.

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