

Assessment of visual impairment and need of rehabilitation services for children attending schools for blind in an urban city of North India

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ABSTRACT

Background/Aims: By understanding the prevalence and causes of childhood blindness, stakeholders can work toward comprehensive strategies that encompass prevention, treatment, rehabilitation, and support, ultimately improving the quality of life for affected children. The information about the pattern and causes of childhood blindness in Northern Indian states is limited, it highlights the need for further research and data collection to better understand and address the specific challenges in this region. Therefore, the present cross-sectional study was planned to ascertain the different causes and patterns of childhood blindness and to understand the barriers to the use of LVAs and its compliance among the students attending schools for the blind in a North Indian State. **Study Design and Setting:** Students from two schools for blind were examined in Chandigarh and its vicinity in North India. The different causes of severe visual impairment/blindness were classified as per the World Health Organization/Prevention of Blindness standard recording form. **Results:** A total of 89 students attending schools for the blind were examined. The mean age was 13.10 years (range = 4–16 years). Male, female ratio was 3.3:1. The major causes of blindness were congenital anomalies (whole globe anomalies 37.08%), followed by retinal conditions (16.7 = 8%), undetermined/other (12.3), and lenticular conditions (11.2%). More than one-third of children (34.8%) were blind due to avoidable causes of blindness. **Conclusion:** The current study data append on the existing national available data about childhood blindness in India. Though the sample size of the current is comparatively low, observed different results as compared to previously published reports from other regions, emphasize the strengthening of pediatric ophthalmology services as well as of low vision services in this particular region of North India.

Keywords: Childhood blindness, low vision, vision impairment

Introduction

It is estimated that the worldwide prevalence of childhood blindness is approximately 1.4 million and it varies according to the socioeconomic status of the countries.^[1,2] The magnitude of childhood blindness is an alarming burden and maximum in the

developing countries of Africa and Asia. In these counties, the overall population and pediatric population, both, are large.^[3,4] The current overall population of India is almost 1.40 billion and there are approximately 2,80,000–3,20,000 blind children in our country.^[5]

Although childhood blindness and severe visual impairment (SVI) as compared to adult blindness contribute to a very small fraction of total blindness, it has a significant impact on children's overall development given the heavy cost of education, emotional and

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Received: 23-03-2024

Revised: 21-05-2024

Accepted: 03-06-2024

Published: 18-10-2024

Access this article online

Quick Response Code:



Website:
<http://journals.lww.com/JFMPC>

DOI:
10.4103/jfmprc.jfmprc_482_24

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How to cite this article: Phulke S, Duggal M, Sandhu R, Kumar S. Assessment of visual impairment and need of rehabilitation services for children attending schools for blind in an urban city of North India. J Family Med Prim Care 2024;13:4642-7.

social developmental delay, and employment opportunities, all these factors directly or indirectly affect the affected child's family as well as to the society.^[6,7]

It has been shown that most parents are unaware of the available schooling systems for blind children and only 5% sought treatment from an ophthalmologist which underscores the importance of intervening early and improving coverage and uptake of services at the primary health care level.^[8,9] Strengthening the strategies for the prevention and treatment of childhood blindness is a primary objective of the World Health Organization's (WHO) VISION 2020- the "Right to Sight" Program. The Vision 2020 program is intended to decrease the existing burden of 75 million blind people by the year 2020 to a target of 25 million.^[10]

The revised "working definition" of low vision (LV) has resulted in an overall increase in the number of people with severe and profound LV, who can be rehabilitated with timely interventions. This new definition is best corrected visual acuity (BCVA) less than 6/18 to the perception of light (PL), provided that the child has functional vision for example for navigation.^[10,11]

The majority of the available data about childhood blindness from developing countries has been acquired from children studying in schools for the blind, which offers several advantages. Researchers can examine a larger number of children with visual impairments (VI) in a shorter time frame. Additionally, standardized methods for assessment can be used by a single observer, making data collection more consistent.

The different causes of childhood blindness can vary in different regions. They are mainly influenced by socioeconomic status, access to healthcare services, and cultural practices in that particular region.^[12-14]

Currently, there is limited data in Northern India about the patterns of childhood blindness in this area, therefore in the current study; we aimed to understand different patterns of childhood blindness and to understand the barriers to the use of LVAs and its compliance.

Material and Methods

This cross-sectional study was conducted from May 2022 to December 2022. A total of 89 students, attending schools for the blind in Chandigarh and its vicinity were screened.

The study was approved by the respective Institutional Ethics Committee of the Principal Investigator. The concerned administrators were informed about the study and its scope. Informed consent was obtained from the participant's parent(s) or caregiver after a detailed explanation of the study. Verbal consent (assent) was taken for all children.

All children up to the age of 16 years, attending schools for the blind and who were cooperative for ocular examination and

refraction were included. Exclusion criteria included children having disabilities such as sensory, physical, and/or intellectual disability.

After obtaining demographic details and relevant information from the caregiver and parents (whenever possible), the distant vision was evaluated for both eyes separately using the Snellens "E" chart. The children, who could not cooperate with the "E" chart, were further assessed by their ability to fix and follow the light. Near vision was assessed by the ability to recognize symbols of 5 mm in size, equivalent to N10. They were categorized into WHO categories of VI and blindness.

To determine the presence or absence of a functional vision for the LV category, the ability of the child to navigate around two chairs by vision alone with a visual acuity of $\leq 6/18$ to light perception was observed. The children, who could not perform this test, were judged on their visual behavior.

The refraction for each child was performed by an optometrist. The visual acuity of each student was recorded using WHO categories of VI and blindness before and after refraction. The children having residual functional vision were offered Low Vision Rehabilitation (LVR) services.

Each child's eye anterior segment was examined using a hand-held slit lamp biomicroscope. Wherever possible fundus was also examined by indirect ophthalmoscopy (IDO) following dilatation. The WHO/Prevention of Blindness (PBL) program's eye examination record for children with blindness and LV was used to categorize the causes of blindness and to record the findings, using the definitions in the coding instructions.^[10]

The anatomical classification of different causes of VI defined which part of the eye had been damaged leading to blindness and VI. The primary cause of VI for each eye and each child, using the WHO classification system was recorded. When the primary cause was different for the two eyes, the most preventable or treatable abnormality was selected as the child-specific cause.

After collecting the baseline information, any child who had bilateral phthisis, staphyloma, or adherent leucoma without a clear history was re-interviewed by the research team. Validated questionnaires were used to collect the data to determine the precise cause of the blindness and graded according to the WHO/PBL ERCB (World Health Organization Prevention of Blindness Examination Record for Childhood Blindness).^[10]

The causes were divided into five major categories depending upon the time of onset of the condition leading to blindness (Hereditary, Intrauterine, Peri-natal, Post-natal, and Unknown). For each child, detailed medical and surgical interventions were recorded and the students requiring more in-depth examination were again seen in a tertiary eye care center.

After recording the data, the children were divided into two groups: one who already using LVA and the other who had

functional vision but had not been prescribed LVA before. The children with functional vision were referred to a tertiary eye care center and reassessed for Low Vision Device (LVD) by an optometrist. Those who had discontinued the use of LVA for any reason were asked to give a reason for the same in a closed-ended questionnaire.

Results

A total of 89 students attending schools for the blinds were examined in two schools. The mean age was 13.10 ± 2.939 years (Range 4–16 years). Of the 89 children, 68 were males and 21 were females. Sixteen children had a family history of blindness. Additional disabilities were found in none of the children.

Table 1 describes the categories of blindness as per WHO criteria.

One child (1.12%) had absolute blindness with no PL (Category V), 81 children (91.01%) were in the WHO Category IV, and seven (7.86%) were in Category III [Table 1].

Anatomical causes of blindness/SVI- The major causes of blindness in the better eye were whole globe anomalies, followed by retinal diseases (16.8%) [Table 2].

Etiological causes- [Table 3].

Unknown etiology remained the main cause of childhood blindness, seen in 58 children (65.16%). Among these 58 children, congenital anomalies were responsible in 23 children (39.6%), followed by lenticular conditions in eight children (13.79%).

Among the 89 children, 27 children (30.34%) were using or had a history of having used LVA. Among them, 11 (40.74%) were comfortable using LVA, whereas 16 children (59.26%) had discontinued using LVAs for various reasons [Table 4]. After screening, three more children were found to have functional vision, and optical devices were dispensed to them.

Discussion

In the present study whole globe anomalies account for 37% of childhood blindness causes and similar results have been observed in previous studies conducted with blind students in North and South India.^[14-16] However, there are also studies from North India that have documented a higher proportion of whole globe anomalies as a main cause of SVI.^[17,18]

Table 1: Categories of Blindness in Students (as per WHO classification)

WHO categories of Blindness	Criteria for Blindness as per presenting distance visual acuity		No of students (%)
	Worse than	Better than or equal to	
Category III	3/60	1/60 or CF at 1 m	7 (7.86%)
Category IV	1/60	Perception of Light	81 (91.01%) (Only PL-58, CF -23)
Category V	No light perception	No light perception	1 (1.12%)
Total			89

CF=Counting Fingers; m=meter; PL=Perception of light

Table 2: Anatomical classification of the causes of VI in the better eye of children

Anatomical site (Total No. Of children)	Causes	No	%	% of Total Children
Whole Globe (33)	Microphthalmos	18	54.54%	37.08%
	Anophthalmos	5	15.15%	
	Buphthalmos**	5	15.15%	
	Secondary glaucoma	0	0	
	Others	5	15.5%	
Cornea (9)	Staphyloma*	5	55.55%	10.11%
	Scar*	4	44.44%	
	Others	0	0	
Lens (10)	Cataract**	4	40%	11.2%
	Psuedophakia**	4	40%	
	Aphakia**	2	20%	
	Others	1	10%	
Retina (15)	Dystrophy	3	20%	16.8%
	Albinism	1	6.6%	
	Retinopathy Of Prematurity (ROP)**	7	46.6%	
	Others	4	26.6%	
Optic Nerve (8)	Optic Atrophy	8	8.9%	8.9%
Uvea (5)	Coloboma	5	5.6%	5.6%
Others (11)	Not specified	3	27.2%	12.3%
	Idiopathic Nystagmus	8	72.7%	

*Preventable causes (9 children; 10.1%). **Treatable causes of blindness (22 children; 24.7%)

Table 3: Etiological classification of the causes of childhood blindness and VI

Etiology	Causes and number of children	Total number of children (%)
Hereditary	Retinal dystrophies: 3 Albinism: 1	4 (4.49%)
Pre-natal/Intrauterine	Intrauterine toxoplasmosis: 1	1 (1.12%)
Peri-natal	ROP*: 7	15 (16.85%)
Post-natal	Optic nerve lesions: 8 Keratomalacia: 9 Trauma: 2	11 (12.35%)
Unknown etiology	Whole globe: 23 Cataract+ pseudophakia: 8 Coloboma: 5 Glaucoma: 5 Others: 17	58 (65.16%)

*ROP=Retinopathy of Prematurity

Table 4: Reasons for discontinuation of LVD and anatomical causes of their blindness

Reason for Discontinuation	No. of Children (Total: 16)	Anatomical cause of blindness (No of cases)
Handling issue (3)	3	Retinal Detachment (1), Coloboma (1), ROP* (1)
Priority not meeting (9)	9	Optic Atrophy (3), Congenital Glaucoma (1), Retinal (1), Congenital Cataract (1), Aphakia (1), Nystagmus (2)
Cosmetic (2)	2	Microcornea/cataract (1), Microphthalmos (1) Nystagmus (1)
Others (2)	2	Coloboma (1), Microphthalmos/coloboma (1)

*ROP- Retinopathy of Prematurity

In the current study, corneal causes accounted for 10% of the ocular conditions being investigated. This percentage is lower compared to previously published reports from different regions in India, where corneal causes were found to be higher (e.g., North-east – 36.5%, Uttar Pradesh – 26.4%, Maharashtra – 32.2%).^[14,17,19] This suggests regional variations in the prevalence of corneal causes. However, recent studies conducted in South India have reported similar results as to this current study.^[16]

It is noted that determining the cause (etiology) of corneal opacity and anterior staphyloma after several years of the original incident is challenging. This could be due to various factors such as lack of medical records, changes in the patient's condition over time, or limited access to healthcare. The lower prevalence of corneal causes in the current study may be attributed to good immunization coverage for measles, Vitamin A supplementation, and nutritional programs run by the local government.

In the present study, retinal diseases were responsible for 16.8% of SVI and blindness. In a population-based study from rural South India, 44.4% of children were found to be blind due to retinal diseases (total sample size of 23,100 children, only 18 children were found to be blind).^[20] Retinopathy of

Prematurity (ROP) (46.6%) contributed as the most important cause of retinal diseases in the present study, emphasizing the importance of ROP as a significant cause of retinal diseases and highlighting its relevance in terms of avoidable blindness.

In the present study, optic nerve diseases accounted for only 8.9% of childhood blindness. This percentage is consistent with the findings of recently published reports, which have also reported similar ranges, typically between 4.6% and 10.8%. However, some earlier studies had documented optic nerve diseases as a major contributor to childhood blindness, suggesting a higher prevalence in that particular region.^[21,22]

In our study, avoidable causes of blindness such as corneal scar or staphyloma, cataract, glaucoma, trauma, and ROP account for 34.8% of all students attending schools for blinds. Our results coincide with the previously published Indian studies.^[17]

In terms of etiological causes, the present study results are similar [children with severe VI of undetermined etiology (65%)] to the previously published reports of Northeast (51.9%), North State-Delhi (63.9%), and Gujarat (63.1%) conducted in the same way in blind children.^[14,18,23] A significant portion (39.3%) of the undetermined etiological causes in the present study were attributed to congenital anomalies. Congenital anomalies can result from genetic or intrauterine factors. In the present study, intrauterine factors could not be assessed due to limited investigations and family member unavailability in many cases.

In a recent report from South India, hereditary factors (40.5%) followed by unknown etiology (35.5%) were the common causes of VI and blindness in children. The difference in the findings could be due to the commonness of consanguineous marriages in South Indian states.^[16]

In the current study, positive family history was present in a total of 16 cases. Among them, three had retinal dystrophy, four had buphthalmos, two had cataracts, and one had Grade 4 coloboma. In the remaining six children, the etiology could not be identified.

The redefinition of VI and LV has improvised the data of actual people having severe and profound low vision. They can benefit from timely and proper responsive care and suitable rehabilitation. The estimated global prevalence of VI, based on BCVA is 1.67%, whereas pediatric blindness is 0.17%.^[3]

LVA can work as an efficient means of providing visual rehabilitation. Various studies have documented children perform better than adults in terms of using LVA if prescribed properly. However, a few recent Indian studies also documented the non-compliance rate of LVD, even if dispensed at no cost and with proper counseling before prescribing LVA to the children attending schools for the blinds.

Chavan *et al.* in 2023,^[19] which focused on identifying the barriers to using Low Vision Aids (LVA) among children attending

schools for the blind in India, found that nearly one-third of children with useful functional vision were not using LVA and spectacles even after a follow-up period of six months.

In their study, it was observed that broken or lost spectacles were the primary cause of non-compliance, accounting for 52% of cases. This suggests that the physical condition and durability of the spectacles may be significant factors affecting their use. Additionally, 24% of cases reported discomfort as a reason for non-compliance, which highlights the importance of comfort and fit in ensuring that individuals, especially children, are willing to wear their spectacles regularly.

The study by Gogate *et al.* in 2013, which focused on compliance with free spectacles among secondary school children, found a similar low compliance rate of 29.5% after six months.^[24] Reasons for non-compliance in this study included “forgot to wear,” “lost,” and “broken,” which aligns with the findings of Chavan *et al.*’s study and underscores the need for addressing issues related to loss, damage, and forgetfulness when providing spectacles to students.^[19]

In a study conducted by V.R. Venkataramanan *et al.*,^[25] cost (7/50), cosmetic blemish (07/50), and priorities not meeting optimally (6/50) were found to be the main reasons for not using LVA by children attending LVA clinic. This suggests that factors like low socioeconomic status and cosmetic blemishes are associated with low LVA compliance. This correlates with Gao *et al.*,^[26] who observed that among 243 patients, 76% of children accepted LVA, whereas 34% of patients refused to use LVA due to high cost, price, troublesome use, younger age, ungraceful appearance, and unawareness.

These studies indicate that factors such as cost, convenience, cosmetic concerns, and lack of awareness or knowledge about LVA can influence an individual’s decision to use LVA.

In the present study, the author also compiled the factors responsible for non-compliance with LVA, already prescribed to children with useful functional and residual vision. After initial examination, 16 children were found to have used LVA in the past. With proper history, different causes for the discontinuation of LVA were ascertained. Among the different causes “priorities not meeting optimally” (56.2%), followed by “handling issues” (18.7%) and “cosmetic” and other “Non-specific causes” (12.5%). The results emphasize the frequent and thorough ophthalmic examination and LVA workup of these children.

Based on these results, it is emphasized that frequent and thorough ophthalmic examinations and LVA workups are essential for these special children. This information suggests that addressing the specific needs and priorities of these children, along with addressing handling issues and cosmetic concerns may help improve the effectiveness of LVA usage and overall visual health for these individuals.

Eyecare programs for childhood blindness screening should be integrated at the primary care level in the community.^[27,28] Systematic monitoring at the community level for timely referral and follow-up can be strengthened through a holistic, child-centered policy involving the parents, caregivers, Anganwadi workers, and teachers need to be adopted. In addition, proper use of vision aids including spectacle, and compliance needs to be appropriately managed through early detection and appropriate treatment.

While the present study contributes valuable insights to the field, this study carries the burden of bias too, as many children in developing countries do not have access to schools for the blind. So, the data could be underestimated as children from poor, having additional disabilities, and from remote rural areas are under-represented.

The mean age of presentation in the current study was 13.0 years, indicating that most of the children attending schools for the blind were born almost 10–13 years ago, so the etiological causes of blindness reported in the present study could be influenced by the different ongoing awareness and preventive policies in the community.

A further constraint of our study is that the etiological causes could not be absolutely reliable, as history was given by children and all participants’ parents were not available at the time of examination.

Conclusion

The current study data append on the existing national available data about childhood blindness in India. It appears to provide valuable insights into childhood blindness in India, despite its small sample size. It emphasizes the need for healthcare improvements in the region it studied, especially in the context of pediatric ophthalmology and LV services.

The importance of the present study lies in its identification of significant gaps in data and services related to childhood blindness and LVA in Chandigarh City. Addressing these gaps can have a profound effect on the lives of visually impaired children and contribute to a more supportive environment for them.

The different causes of blindness in students of Chandigarh appear to be distinct from what is observed in other North Indian states. This suggests that factors specific to Chandigarh, such as demographics, healthcare access, or environmental factors, may be influencing the pattern of different causes of blindness.

Further research and data analysis may be needed to fully understand the unique aspects of childhood blindness in Chandigarh and to develop targeted strategies for addressing these issues.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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