Changing pattern of childhood blindness in eight North-Eastern states and review of the epidemiological data of childhood blindness of India

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Purpose: To assess the causes of visual impairment and blindness in children in all the schools for the blind in eight northeastern states and to determine its temporal trend, and to analyze the result with reference to various regional epidemiological data on childhood blindness in India. **Methods:** Children aged <16 years, with a visual acuity of <6/18 in the better eye, attending 17 schools for the blind were examined between November 2018 and March 2020. WHO protocol and reporting format was used for the evaluation, diagnosis, and classification of the causes. **Results:** Out of 465 eligible study participants, 93.76% were blind and only 12.26% of causes were avoidable. Anatomical causes of childhood blindness were whole globe (43.2%), cornea (17.20%), optic nerve (12.04%), retina (9.68%), and lens (9.46%). Etiological causes were unknown (52.69%), hereditary (26.02%), intrauterine (15.05%), and 26.08% had blinding congenital ocular abnormality (s). Regional temporal trend revealed a decrease in corneal and childhood causes and an increase in retina, optic nerve, hereditary, and intrauterine causes. **Conclusion:** A constellation of causes were differentiable but matched with the overall emerging trend of childhood blindness in India. Higher corneal, unavoidable, and unknown causes suggest a region-specific action plan for controlling childhood blindness as well as rehabilitation.



Key words: Childhood blindness, congenital ocular anomaly, corneal blindness, school for the blind

Childhood blindness (CHB) depends on the socioeconomic development of a region and is a priority action area of the World Health Organization (WHO). CHB is not only a predictor of under-5 mortality^[1] but also indicates the overall state welfare and health. It causes Lowenfeld losses (Lowenfeld losses are the limitations that are imposed on a blind person. They are mainly classified as follows: (1) Loss of range and variety of experiences; (2) Loss of the ability to get around; (3) Loss of control of the environment and the self in relation to it.) and an increase in disability-adjusted life years, resulting in devastating consequences that are otherwise preventable with the application of proper public health strategies in at least 50% of the cases.^[2,3] An estimated burden of 11.2 million blind person-years caused by CHB in India in the recent past^[4] may get aggravated because 41% of the present population of the country is below 18 years of age.^[5] The problem of CHB in Northeast India is apprehended to be more complex because of geopolitical distance, cultural and ethnic diversity, and a lower development index of the region.^[6] Reliable data from the entire country's population is ideal for developing a roadmap and targeted programmes to control CHB.[2,7] In settings with limited resources, blind school survey data in standard WHO format are used with the inherent limitation and potential bias of gross assessment of causes and burden of CHB, while its temporal trend study is an indicator of the impact of an intervention.^[2,4,8] Indian epidemiological data on

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Received: 30-Apr-2021 Accepted: 13-Aug-2021 Revision: 13-Jun-2021 Published: 23-Dec-2021 CHB are limited and centered on five population-based surveys conducted in South India^[8-12] and 18 region-specific studies that were conducted in the schools for blind children in India.^[13-29] Two of these studies were temporal trend analysis conducted in the same schools in two geographical regions (Delhi and Dehradun and Pune)^[14,24] and only one has been conducted in Northeast India.^[21] Considering these facts, the present research was carried out to determine the causes of severe visual impairment/blindness (SVI/BL) among the children from 17 schools for the blind, spread out in eight northeastern states, and to discuss the findings of the studies with regards to the epidemiological data and changing trends in the domain of CHB in India over the previous six decades and in comparison with our previous study^[21] in order to ascertain temporal trends in the causes of blindness in Northeast India.

Methods

Blindness (BL) was defined as presenting visual acuity of <3/60 in the better eye and SVI as best-corrected visual acuity in the better eye <6/60 but equal to or better than 3/60 (WHO and NPCB and VI criteria).^[30] In this study, 0–16-year-old children were considered as per UNICEF definition.

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The protocol of the study was approved by the review board of the institution and adhered to the Declaration of Helsinki. All students that were enrolled in the 17 schools for the blind over eight northeastern states (Assam, Meghalaya, Tripura, Manipur, Arunachal Pradesh, Mizoram, Sikkim, and Nagaland) were examined between November 2018 and March 2020. The schools were enlisted from individual state blindness control societies. District administrations were contacted and approval for conducting the study and examination was obtained from the authorities and the principal of the schools. The liaison, coordination, and logistics were arranged by the study coordinator, volunteer, and members of Lions Club Guwahati Care. The examination procedure was noninvasive as per WHO prevention of blindness eye examination protocol. Demographic information was obtained from the students, teachers, and parents (if available). A brief history of the place of residence, family history, and consanguinity of the parents was elicited and recorded. Any history of trauma, systemic disease, malnutrition (including vitamin A deficiency), and additional disabilities was obtained from the medical records of the children, which were available in the school.

The survey team comprised of ophthalmologists, four optometrists, three data entry operators, one project coordinator, and four volunteer members from the Lions Club Guwahati Care. The team members were trained regarding the protocol, detailed method of examination, data recording, and validation of data, and verification of findings by the pediatric ophthalmology department of Sri Sankaradeva Nethralaya, Guwahati.

Distance visual acuity was measured using a logMAR E-Chart and near vision was N18 (equivalent). The vision of each eye was tested separately. A distance of 3 m was used for the children with visual acuity <6/60. If the presenting vision was <3/60, the child was then progressively brought closer to the chart until the subject was able to read the top letter at 1 m, failing which, finger counting was tried, and lastly, the perception of light and projection of rays in four quadrants was tested. Independent ability to navigate with one assistant between chairs set 2 m apart in a well-lit room was used to assess the residual vision for independent mobility. Recognition of faces at a distance of 2 m and shapes of the symbols at 2 cm from the eye was used to assess the ability of the child to socially interact.

External examination of the face and ocular adnexa was done using a torchlight. The anterior segment was examined with a handheld slit lamp (Make-Shin Nippon, Japan, Model-XL-1). The posterior segment examination was done where possible, following mydriasis, using an indirect ophthalmoscope (20D Diagnostic lens. Make- Volk, USA. Part No-BIO 7185. Double Aspheric). For each eye of every child, one major anatomical site and the underlying cause were selected. In case of more than two causes, the preventable or treatable cause was coded first. Regarding hereditary conditions, an assumption of autosomal dominant transmission of a disorder (in absence of genetic testing) was based on the clinical findings and a few general principles such as i) each affected child has an affected parent, ii) males and females are equally affected in the family, and iii) vertical transmission of the disorder occurs through successive generations. Any need for optical correction, medical treatment, and surgical intervention and the visual prognosis was assessed, and subjects requiring any such treatment were mobilized to the base hospital with the help of the (Lions Club Guwahati Care) and the district authority for appropriate action. WHO/PBI standardized eye examination records for children and low vision were used to categorize the cause of blindness and to record the findings. Definition of coding instruction was followed in each case.^[31] Data were recorded on an Microsoft Excel Sheet and STATA13 (Stata Corp LLC, Texas, USA) software was used for data analysis. Test of significance was carried out using Pearson's Chi-Square Test. An alpha level of 5% was taken; P < 0.05 was considered as significant. The study was conducted after obtaining approval from the institutional ethics committee dated 06/05/2017.

Results

A total of 465 students of 17 schools for blind children were examined. There were seven schools from Assam, one from Arunachal Pradesh, two from Manipur, two from Meghalaya, two from Mizoram, one from Sikkim, and two from Tripura. Before 2008, only 12 schools for blind children (SBC) were functioning and the first school was established in the state of Tripura (1972). Despite the schools being located in different geographical regions, these studies did not represent the entire population, its subgroup, and different tribes of the region. This prospective study was conducted from November 2018 to March 2020. The highest number of study participants were from Assam. The mean age of the students was 12.79 ± 2.81 years (range: 3–16 years); 264 (56.8%) were boys and 201 (43.2%) were girls. Systemic and other disabilities were found in 28 (6.02%) students; the most common systemic disability was mental retardation (8) and deafness (6), and the least common was autism and Down syndrome (one case of each). State-wise distribution of the schools, number of students in each school, gender, and mean age of the study participants is listed in Table 1. History of consanguinity was present in 7.09% of cases and 26.08% of children were born with congenital ocular defects.

Out of 551 students, 465 were examined. Out of them, 436 (93.76%) children were blind. Fourteen (3.01%) children had SVI, 7 (1.5%) children had moderate visual impairment, and the remaining 8 (1.72%) had a visual acuity of 6/18 or better. The categories of visual impairment and blindness after best correction of refraction and state-wise distribution are tabulated in Table 1.

The main anatomical causes of CHB and SVI [Table 1] were whole globe anomaly ($\eta = 199, 42.80\%$), cornea ($\eta = 80$, 17.20%), optic nerve (η =50, 12.04%), retina (η = 17, 3.66%), uvea $(\eta = 11, 2.37\%)$, and others $(\eta = 13, 2.80\%)$. Among the whole globe anomaly, the most frequent cases were of congenital abnormality of the eye, including microphthalmos ($\eta = 147$, 31.61%), anophthalmos ($\eta = 39$, 8.41%), and the acquired phthisis bulbi ($\eta = 12, 2.6\%$). The corneal causes of SVI and CHB were corneal scar (η = 56, 12.06%) and staphyloma due to unknown causes (η = 12, 10.13%). Optic nerve causes consisted of optic nerve hypoplasia ($\eta = 6$, 1.32%). Dystrophy ($\eta = 10$, 2.61%) was an important retinal cause. Cataract ($\eta = 27, 5.83\%$) was the most frequent lenticular cause, and next to that was pseudophakia (η = 13, 2.81%). Coloboma (η = 11, 2.38%) was the main uveal cause and buphthalmos ($\eta = 9, 1.95\%$) was the commonest variety of glaucoma amounting to CHB. In the

Table 1: Summary of es regions of India (1966-2 (\$) Visual acuity for blir present study were tem	itimates of children (021) in percentage. Idness calculated 6/ poral trend studies	with seve (*) globe 60, (NA) in the sa	ere visual appears r data not a me schoo	loss ar ormal, vailable s	nd blinc (**) no e, (@) f	lness b t exami rom a c	y anato ned, (** lisserta	mical *) oth tion, L	site o ers no ondo	f abno it liste n Univ	d, (***) d, (***) ersity, 1	in the school unknown, (#) 998. Dada <i>et</i>	for the bli remaining <i>al.</i> 1984, Is	nd child childrei srafil <i>et</i> ,	lren in di מ were n <i>al</i> . 2014 מ	fferent ormal, ind the
Year Author	Area of study	Number of blind schools	Total No. of blind Children examined	Age F in years	emale	Whole (globe	Cornea	Lens L	Vea R	etina	Optic No nerve n	ot examined/ G ormalglobe/ unknown/ others	àlaucoma N	loderate VI	Severe E VI	lindness #
1966 Mohan <i>et al.</i> ^[13]		NA	NA	AN	AA	ω	75.1			17		7.9***		NA	NA	NA
1984 Dada <i>et al</i> . ^[14]	Delhi & Dehradun	NA	200	NA	NA	17	55.5	7	3.5	5.5	11.5		-	÷	6.5	06
1993 Gilbert <i>et al.</i> ^[15]	South India	NA	305	3-28	NA	20	38.4	7.4	2	22.6	5.6	*	ю	5.8	6.7	86
1995 Rahi <i>et al.</i> ^[16]	9 states	22	1318	3-15	42	25.3	26.4	12.3	5.8	20.7	5.9	0.9***	2.6	5.7	80	85.4
2000 Hornby <i>et al.</i> ^[17]	Andhra Pradesh	9	291	5-15	37.1	20.2	24.3	7.9	3.4	31.1	4.9	1.5***	6.7	ΝA	NA	91.7
2001 Gilbert and Foster ^[18]	West Bengal	NA	1890	≤15	ΝA	24	28	ŧ	5	22	9	1 ****	ю	ΝA	NA	NA
2003 Titiyal <i>et al.</i> ^[19]	Delhi	13	650	≤16	38.5	27.4	21.7	10.9	8.8	15.1	10.6	0.6***	4.9	3.7	2.8	92.9
2007 Gogate <i>et al.</i> ^[20]	Maharashtra	35	1778	≤16	44	41.3	22.2	9		11.2		19.3***		0.6	3.7	95.4
2008 Bhattacharjee et al. [21]	8 Northeast states	12	258	≤16	41.8	36.1	36.4	10.9	2.3	5.8	5.4	3.1***		0.8	6.9	92.3
2009 Gogate <i>et al.</i> ^{[22]\$}	Karnataka	NA	891	≤16	ΝA	35.7	14.9	11.4		19.9		18.1**			7.8	92.2
2012 Krishnaiah <i>et al.</i> ^[23]	Kakinara, South India	9	113	4-15	44.2	41.4	8.1	9.9	4.5	18.9	6.3	10.8***		1.8	7.1	91.2
2014 Israfil <i>et al.</i> ^[24]	Maharashtra	NA	460	5-20	46.5	30.9	13	16.9	ß	9.3	9	18.9***				
2015 Bhalerao <i>et al.</i> ^[25]	Allahabad	4	06	s<20	27.8	54.44	24.45	10	1.1	3.3	6.67			0	7.78	06
2015 Danayak <i>et al.</i> ^[26]	Gujarat	ო	179	≤16	100	42.4	24	7.3	3.9	11.7	10.6					
2017 Prakash <i>et al</i> . ^[27]	Chennai	N	302	5-16	53.3	N	15.6	12.9		18.2	24.8	19.9***	6.6	0	0	100
2018 Agarwal <i>et al.</i> ^[28]	Uttar Pradesh	Ŋ	93	5-16	22.6	40.3	26.4	6.9	11.1	8.3	4.2	2.8***				
2020 Panda <i>et al.</i> ^[29]	Andhra Pradesh & Telengana	10	259	4-15	37.8	32	11.2	17	0.4	26.6	7.3	5.4*		9	5.4	82.9
2021 Bhattacharjee <i>et al.</i> (Present Studv)	8 Northeast states	17	465	3-16	43.2	42.8	17.2	9.46	2.37	9.68	12.04	2.8***	3.66	1.5	3.01	93.7

"Other" category, pathological myopia ($\eta = 12, 2.61\%$) was the commonest cause. Microphthalmos, anophthalmos, optic nerve hypoplasia, retinal dystrophy, cataract, uveal coloboma, and buphthalmos were the congenital abnormalities of the eye. The anatomical site of the lesion responsible for severe vision loss and blindness and its distribution are shown in Table 1.

Etiological categories of SVI and CHB are shown in Table 2. In the majority of cases, ($\eta = 245$, 52.69%) the etiology could not be established. Subsequent causes in decreasing order of frequency were hereditary ($\eta = 121$, 26.02%), intrauterine ($\eta = 70$, 15.05%), childhood factors ($\eta = 26$, 5.59%), and perinatal causes ($\eta = 3$, 0.65%). In the undetermined groups, the deformity of the globe was present since birth. The mode of transmission was undetermined ($\eta = 113$, 24.28%) in most cases. The transmission was autosomal dominant ($\eta = 7$, 1.52%) and autosomal recessive ($\eta = 1$, 0.22%) in the remaining cases in the hereditary group. Trauma accounting to CHB was only in two cases. The state-wise distribution of anatomical causes of CHB was statistically significant (*P* = 0.00001) [Table 3].

In the present study, blindness was avoidable in 12.26% ($\eta = 57$) of children [Table 2]. The important preventable cause was ocular abnormality due to transmitted autosomal dominant eye disorder ($\eta = 7$, 1.52%) [Table 4]. Other causes included vitamin A deficiency ($\eta = 1$, 0.2%) and trauma ($\eta = 1$, 0.2%), with one case each respectively (as indicated by medical records and positive history). The important treatable causes were cataract ($\eta = 27$, 5.8%) and glaucoma ($\eta = 17$, 3.66%). Blindness due to retinopathy of prematurity was detected in one case. The remaining 87.7% of children were blind due to

unavoidable causes such as congenital anomalies and other acquired causes. Reasons for persistent visual loss in children who underwent cataract surgery and IOL implantation were nystagmus, other associated ocular anomalies, amblyopia, and posterior capsular opacity alone or in combination.

Discussion

Prevalence of SVI/Blindness (BL) among the children in South Indian states from 2003 to 2018 varied from 0.06% to 0.37%.^[8-12] Major causes of SVI/BL in the population were whole globe anomaly (25%–30.56%),^[12] lens (27.7%),^[11] cornea (14%–20%)^[8], and uveal coloboma.^[11,12] Corneal causes subsequently declined and were reduced to an insignificant proportion. Refractive errors, once as high as 40%,^[8] were subsequently not an issue; while retinal causes relatively maintained a higher prevalence (28.6%–44.5%)^[8,11] in some studies. Data on population-based studies from other parts of India are not available.

Epidemiological data collected in the SBC revealed that leading anatomical causes of SVI/BL and frequency of different anatomical sites of lesions causing blindness varies between the studies. But over time, a changing trend in the frequency and distribution of anatomical causes of SVI/BL in children has been observed. A similar change is also observed in etiological causes. Temporal trend study of anatomical causes showed the increased contribution of whole globe anomalies, from 8%^[13] to 54.4%^[25], to become one of the leading causes of SVI/BL currently. Previously leading corneal causes declined from the initial 75%^[13] to 8%^[23] at present. Retina and optic nerve causes

Table 2: Summary of estimates of number of children with severe vision loss and blindness by etiolgical category in the school for the blind children of India (1966-2021) in percentage (along with avoidable blindness and congenital causes). (NA) data not available. Consanguinity found in %: 1. Bhattacharjee *et al.* 2008 (6.4%), Krishnaiah *et al.* 2012 (48.7%), Bhalerao *et al.* 2015 (5.6%), Panda et al. 2020 (37.8%), Bhattacharjee *et al.* 2021 (7%), and in the remaining studies, consanguinity was not mentioned

Author and year		Etio	logical Categ	ory		Avoidable and Congenital Causes				
	Heriditary %	Intrauterine %	Perinatal %	Childhood %	Unknown %	Avoidable blindness %	Congenital causes %			
Mohan <i>et al</i> . 1996	8	_	-	92	-	NA	NA			
Dada <i>et al</i> . 1984	24	-	-	75.5		84.5	24			
Gilbert <i>et al</i> . 1993	29.8	1.3	2.3	37	29.6	47	NA			
Rahi <i>et al</i> . 1995	22.9	1.8	1.4	27.9	46	47.3	22			
Hornby <i>et al</i> . 2000	34.8	0.4	2.6	24	38.2	35.9	46.1			
Gilbert and Foster 2001	26	1	2	29	42	NA	NA			
Titiyal <i>et al</i> . 2003	13.4	0.9	1.2	28	56.5	43.5	13.4			
Gogate et al. 2007	13.7	4.6	1.4	11.1	69.2	34.5	41.1			
Bhattacharjee et al. 2008	7	1.6	1.2	38.4	51.9	48.3	36.1			
Gogate et al. 2009	28.1	NA	NA	13.4	NA	27.8	35.7			
Krishnaiah <i>et al</i> . 2012	17.1	0.9	5.4	8.1	68.4	28.8	41.4			
Israfil <i>et al</i> . 2014	NA	NA	NA	NA	NA	53.8	NA			
Bhalerao <i>et al</i> . 2015	11.56	NA	NA	NA	31.11	47.7	52.2			
Danayak <i>et al</i> . 2015	10.1	0	1.7	25.1	63.1	46.4	NA			
Prakash <i>et al</i> . 2017	21.5	NA	NA	NA	10.9	31	NA			
Agarwal <i>et al</i> . 2018	56.9	-	-	13.8	29.1	24.8	40.8			
Panda <i>et al</i> . 2020	40.5	12	5	6.9	35.5	37.1	NA			
Bhattacharjee et al. 2021	26.02	15.05	0.65	5.59	52.69	12.3	26.08			

Anatomical Site	Arunachal Pradesh		As	sam	Meg	Meghalaya Manipur			Mizoram Nagaland			Sik	kim	Trij	oura	Т	otal	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%	No	%	No.	%
Whole globe	5	1.08	108	23.23	23	4.95	15	3.23	8	1.72	8	1.72	10	2.15	22	4.73	199	42.80
Microphthalmos	4	0.86	75	16.13	18	3.87	12	2.58	6	1.29	6	1.29	10	2.15	16	3.44		
Anophthalmos	1	0.22	25	5.38	4	0.86	1	0.22	1	0.22	2	0.43	-	-	5	1.08		
Phthisis	-	-	7	1.51	1	0.22	2	0.43	1	0.22	-	-	-	-	1	0.22		
Others	-	-	1	0.22	-	-	-	-	-	-	-	-	-	-	-	-		
Cornea	2	0.43	25	5.38	15	3.23	8	1.72	6	1.29	4	0.86	6	1.29	14	3.01	80	17.20
Staphyloma	-	-	3	0.65	5	1.08		-		-	2	0.43	1	0.22	1	0.22		
Scar	2	0.43	21	4.52	9	1.94	7	1.51	6	1.29	2	0.43	5	1.08	4	0.86		
Others	-	-	1	0.22	1	0.22	1	0.22		-		-		-	9	1.94		
Lens	0	-	15	3.23	10	2.15	9	1.94	1	0.22	1	0.22	2	0.43	6	1.29	44	9.46
Cataract	-	-	9	1.94	6	1.29	5	1.08	1	0.22	1	0.22	1	0.22	4	0.86		
Aphakia	-	-	-	-	-	-	1	0.22	-	-	-	-	1	0.22	1	0.22		
Pseudophakia	-	-	6	1.29	3	0.65	3	0.65	-	-	-	-		-	1	0.22		
Others	-	-	-	-	1	0.22	-	-	-	-	-	-	-	-		-		
Retina	6	1.29	10	2.15	6	1.29	9	1.94	5	1.08	2	0.43	-	-	7	1.51	45	9.68
Dystrophy	2	0.43	2	0.43	2	0.43	1	0.22	1	0.22	-	-	-	-	2	0.43		
Others	4	0.86	8	1.72	4	0.86	8	1.72	4	0.86	2	0.43	-	-	5	1.08		
Optic nerve	0	-	16	3.44	8	1.72	7	1.51	9	1.94	2	0.43	5	1.08	9	1.94	56	12.04
Atrophy	-	-	15	3.23	7	1.51	5	1.08	7	1.51	1	0.22	4	0.86	8	1.72		
Hypoplasia	-	-	1	0.22	1	0.22	-	-	1	0.22	1	0.22	1	0.22	1	0.22		
Others	-	-	-	-	-	-	2	0.43	1	0.22	-	-	-	-	-	-		
Uvea	1	0.22	4	0.86	3	0.65	-	-	3	0.65	-	-		-	-	-	11	2.37
Coloboma	1	0.22	4	0.86	3	0.65	-	-	3	0.65	-	-		-	-	-	11	
Others	-	-	-	-	-	-	-	-	-	-	-	-		-	-	-		
Glaucoma	0	-	8	1.72	3	0.65	4	0.86	-	-	-	-	2	0.43	-	-	17	3.66
Buphthalmos	-	-	5	1.08	1	0.22	3	0.65	-	-	-	-		-	-	-		
Glaucoma	-	-	3	0.65	2	0.43	1	0.22	-	-	-	-	2	0.43	-	-		
Others	1	0.22	1	0.22	3	0.65	3	0.65	3	0.65	-	-		-	2	0.43	13	2.80
High pathological myopia	1	0.22	1	0.22	3	0.65	3	0.65	3	0.65	-	-	-	-	1	0.22		
High hypermetropia	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0.22		
Cortical blindness	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-		
Total	15		187		71		55		35		17		25		60		465	100

Table 3: Anatomical site of severe visual impairment and blindness in children examined in schools of northeastern states of India

have shown a rising trend from 3.3% to 31.1% and from 4.2% to 24.8%, respectively. Lenticular causes have been somewhat stable between 6% and 17% in different studies. Most children of those schools were blind (82.9%–100%) and only a few had SVI (0%–8%). The avoidable blindness has also declined from initial at 84.5% to 40% presently. A summary of the estimate of children (in percentage) with severe visual loss and blindness by anatomical site of abnormality in the various SBC of India between 1966 and 2021 is tabulated in Table 1 and graphically represented in Fig. 1.

On reviewing the data on SVI/BL according to etiology, from different schools for the blind, variations and interim fluctuation between different studies both in causes as well as their proportion in percentage were found. However, a trend was observed. Hereditary and intrauterine causes are rising proportionately. At the same time, unknown causes are also increasing from an initial 29.6%^[15] to the present 35.5%^[29], with

an interim high spike recorded in one study in 2007.^[20] The perinatal causes are more or less constant. Childhood causes remarkably declined from the initial 92%^[13] to the present 6.9%.^[29] Avoidable causes have also shown a declining trend from the initial 84.5%^[14] to the present 37.1%.^[29] Summary of estimates of the number of children with severe vision loss and blindness by etiology in the schools for the blind children of India from 1996 to 2021 in percentage is shown in Table 2 and graphically represented by Fig. 2. Consanguinity was found higher in South India^[23,29] in comparison to the north^[25] and Northeast India.^[21] Congenital ocular abnormalities such as microphthalmos, anophthalmos, uveal coloboma, and congenital cataracts together have a rising trend from an initial 24.5%^[14] to present 40.80%.^[28] However, the same was reported to be as high as 52.2% in one study.^[25]

Comparing the data from the present study with the entire epidemiological data of India on SVI/BL revealed that the

	Aruna Prad	achal lesh	Ass	sam	Meghalaya		Mar	nipur	Mizo	oram	Naga	aland	Sik	kim	Trip	oura	Т	otal
	No	%	No	%	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Preventable																		
Vitamin A deficiency/measles	-	-	1	0.2	-	-	-	-	-	-	-	-	-	-	-	-		
TORCH/meningitis	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0.2		
Autosomal dominant	-	-	3	0.6	1	0.2	-	-	-	-	-	-	-	-	3	0.6		
Trauma/harmful traditional eye remedies	-	-	1	0.2	-	-	-	-	-	-	-	-	-	-	2	0.4		
Subtotal:	0		5	1.1	1	0.2									6	1.3	12	2.58
Treatable																		
Cataract	-	-	9	1.9	6	1.3	5	1.1	1	0.2	1	0.2	1	0.2	4	0.9		
Glaucoma	-	-	8	1.7	3	0.6	4	0.9	-	-	-	-	2	0.4	-	-		
Uveitis	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-		
ROP	-	-	1	0.2	-	-	-	-	-	-	-	-	-	-	-	-		
Subtotal	0		18	3.9	9	1.9	9	1.9	1	0.2	1	0.2	3	0.6	4	0.9	45	9.68
Total avoidable	0		23		10		9		1		1		3		10		57	12.26
Total No. of patients in the study	15		187		71		55		35		17		25		60		465	

Table 4: Avoidable causes of severe visual impairment and blindness among children examined in schools of northeastern states of India



Figure 1: Chart showing the distribution of the estimates of children with severe visual loss and blindness by anatomical site of abnormality in the school for blind children of India (1966–2021) in percentage

findings of our study match with the nationwide general trend of a shift in the causes of childhood blindness from

nutritional and infective corneal causes to the whole globe anomalies,^[4] barring the following variations- In Northeast



Figure 2: Chart showing the distribution of estimates of children with severe vision loss and blindness by etiolgy in the school for the blind children of India (1966–2021) in percentage

India, so far, in the anatomical category of SVI/BL, whole globe (42.80%), retina (9.68%), optic nerve (12.04%), and lens (9.46%)-related causes are relatively higher. Uveal causes are more or less constant. Although the corneal causes have declined to 17.20%, it is still higher in comparison to studies from other Indian regions.^[23] Regarding the etiological causes, a major portion of blindness in our region is due to unknown causes (52.69%) and it matches with other studies.[16,19,26] The second-most-common etiological cause is hereditary (26.02%), and it falls within the reported range by other works, but intrauterine causes (15.05%) are much higher in comparison to other studies.^[15-20] Childhood (5.59%), perinatal (0.65%), and avoidable (12.26%) portion of childhood blindness is notably low in the northeastern region. The proportion of congenital causes is the same as that found in other studies [Tables 1 and 2 and Figs. 1 and 2].

On studying the regional temporal trend in Northeast India, a decline in the corneal causes by approximately 50% (from 36.4% to 17.20%) has been observed, but it is still higher than the national standard and therefore is yet to reach the desired target. The whole globe anomaly has increased marginally from 36.1% to 42.8%. Optic nerve and retinal causes together increased almost twofold. The percentage of lenticular and uveal causes remains almost the same. Congenital glaucoma has been found as a new entity (3.66%) in the present study. A marginal increase in the proportion of blind children (BL) and a decline of students with SVI has been observed. Based on etiology, a skew deviation in the trend is observed. Hereditary (7.0%-26.02%) and intrauterine causes (1.6%-15.06%) have notably increased. Childhood (38.4%-5.59%), perinatal (1.2%-0.65%) and congenital causes (36.1%-26.08%) have declined. Unknown causes almost remain the same at approximately 50%, whereas avoidable blindness decreased from 48.3% to 12.26% and unavoidable causes have almost doubled (from 51.7% to 87.7%) in 12 years between our two studies.^[21]

In the present study, variation in the anatomical causes of CHB found between students of different schools for the blind in northeastern states was statistically significant. It suggests that anatomical causes of blindness in children may depend on tribes and ethnicity. However, these schools collectively do not have students representing all of the 220 ethnological groups^[6] in the northeastern states. The low rate of consanguinity in the northeast represents the north, south, dichotomy, and regional variation of cultures in India.[32] Variation in the findings is possible because of the inherent complexity of any epidemiological investigation, which depends on multiple variables and disease dynamics.^[33] A change in the profile of CHB in northeastern states indicates an overall socioeconomic development and effective implementation of the National Program for Control of Blindness and Visual Impairment and Rashtriya Bal Suraksha Karyakram. The decline in childhood and overall causes also indicates effective pediatric eye care intervention despite the high maternal mortality rate^[34] and low development index of the region.^[6]

The overall profile of congenital cataract, pseudophakia, and amblyopia together with other findings such as an increase in unknown, hereditary, and intrauterine causes (although there is a relative reduction in congenital causes,) indicates a region-specific need for genetic and fetal medicine services. A high proportion of unknown causes calls for research to find the etiology and accordingly plan action. There is scope for further development of infrastructure, capacity building, and community-based rehabilitation for children who are irreversibly blind.

Extrapolation of blind school data cannot determine the prevalence and causes of SVI/BL of the entire child population of the region. It needs population-based studies involving proper representative samples of the entire population and its subgroups and other relevant data. In the absence of that, the epidemiological data obtained from SBC will remain the cornerstone in guiding the health policy. In the panorama of CHB, the shifting trend in causes of childhood blindness in the Northeast, as well as other parts, of India does not match with higher income countries where cerebral visual impairment and optic nerve anomalies are the main causes of SVI/BL in children.^[35]

Pending a population-based study on pediatric blindness, we wish to draw the attention of the policymakers, justifying the need for more tertiary eye care centers in the region and the early detection as well as treatment facilities of pediatric eye diseases that can cause blindness. Other needed preventive measures of childhood blindness will be the improvement of maternal and child healthcare, introduction of genetic and fetal medicine services, establishment of skill development and training centers, setting up of rehabilitation centers and increasing the availability of low-vision centers, and focusing on self-employment and community-based rehabilitation for the blind.

Conclusion

The leading anatomical site of lesion causing blindness among children in the schools for the blind in Northeast India was whole globe anomaly. The next frequent causes were corneal, optic nerve, retinal, and lenticular diseases, respectively. Based on etiology, the "unknown" causes category was notably leading. Hereditary, intrauterine, and childhood causes were the other etiologies frequency-wise, respectively. Consanguinity was very low. One-fourth of blindness is attributed to congenital causes. The distribution of anatomical causes of blindness in each northeastern state was statistically significant. No skew deviation was observed in comparison to the findings in other works, except for high unavoidable and unknown causes of childhood blindness in the region. In the past 12 years, there has been a decline in the corneal causes and a twofold increase in retinal and optic nerve causes, whereas whole globe abnormalities have only marginally increased. From childhood causes, the etiology has shifted to hereditary and intrauterine causes, whereas the unknown causes category has maintained an equal proportion in both studies.

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Conflicts of interest

There are no conflicts of interest.

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