WORLD VIEW

Causes and temporal trends of blindness and severe visual impairment in children in schools for the blind in North India

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Aims: To describe the causes of severe visual impairment and blindness (SVI/BL) in children in schools for the blind in north India, and explore temporal trends in the major causes.

Methods: A total of 703 children were examined in 13 blind schools in Delhi. A modified WHO/PBL eye examination record for children with blindness and low vision which included sections on visual acuity, additional non-ocular disabilities, onset of visual loss, the most affected anatomical part of the eye concerning visual impairment, and the aetiological category of the child's disorder based on the timing of insult leading to visual loss was administered in all children.

Results: With best correction, 22 (3.1%) were severely visually impaired (visual acuity in the better eye of <6/60) and 628 (89.3%) children were blind (visual acuity in the better eye of <3/60). Anatomical sites of SVI/BL were whole globe in 27.4% children, cornea 21.7%, retina 15.1%, and lens 10.9%. The underlying cause of visual loss was undetermined in 56.5% children (mainly abnormality since birth 42.3% and cataract 8.3%), childhood disorders were responsible in 28.0% (mainly vitamin A deficiency/measles 20.5%), and hereditary factors were identified in 13.4%. Study of temporal trends of SVI/BL by comparing causes in children in three different age groups—5–8 years, 9–12 years, and 13–16 years—suggests that retinal disorders have become more important while childhood onset disorders (particularly vitamin A deficiency) have declined.

Conclusions: Almost half of the children suffered from potentially preventable and/or treatable conditions, with vitamin A deficiency/measles and cataract the leading causes. Retinal disorders seem to be increasing in importance while childhood disorders have declined over a period of 10 years.

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The control of blindness in children is one of the priority areas of the World Health Organization's "Vision 2020—the right to sight" programme. This is a global initiative, which was launched by WHO in 1999 to eliminate avoidable blindness worldwide by the year 2020. The priorities for control in the first phase are cataract, onchocerciasis, trachoma, and refractive errors and low vision.[1] Although blindness in children is relatively uncommon, this age group is also considered a priority as severe visual loss in children can affect their development, mobility, education, and employment opportunities, which can have far reaching implications on the quality of life of children and affected families.

The prevalence of blindness in children ranges from approximately 0.3/1000 children in affluent regions to 1.5/1000 in the poorest communities.[2] Globally there are estimated to be 1.4 million blind children, almost three quarters of whom live in developing countries.[3] The population of India in 2001 was estimated to be 1.03 billion, approximately 420 million of whom are children under 16 years of age (40.9%).[4] Overall, there are probably 280 000–320 000 blind children in India. In affluent countries there are thought to be approximately 60 blind children/million total population whereas in India there are likely to be between 100 and 400.[5]

Reliable, population based data on the causes of blindness in children are difficult to obtain in developing countries as registers of the blind do not exist, and very large sample sizes would be required for formal cross sectional surveys. Alternative sources include the use of key informants, and examination of children identified as blind in community based rehabilitation programmes. Examination of children in special education has increasingly been used to provide data on the causes of blindness in children, but possible sources of bias need to be borne in mind. The advantages of blind school studies are that many children can be examined in a standard manner by a limited number of observers. The classification system developed by the WHO has been used in several blind school studies over the past 10 years, which allows causes to be compared.

The primary objectives of the present study were to determine the causes of blindness in children in schools for the blind in north India, to ascertain temporal trends in the causes of blindness by analysing the data by age group, and to compare the findings of this study with data obtained from other states in India almost 10 years ago. Being the national capital of India with a population of 13.8 million, and situated in the central part of north India, most blind schools of north India are located in Delhi admitting children from various north Indian states.[4]

PATIENTS AND METHODS

Thirteen schools for the blind in Delhi were visited between July 2000 and May 2001 after obtaining permission for the study from the school principals. Where feasible, parents were present on the day their child was examined.

Relevant information was collected from the class teacher, parents (whenever possible), by reviewing school medical records and by administering a semi-open ended questionnaire to the children. A brief history of the age of onset of visual loss, involvement of other members of the family, the place of residence, and whether the parents' marriage was consanguineous was recorded. Additional disabilities like mental retardation, physical handicap, epilepsy, hearing loss and others were recorded according to the child's medical records. Detailed eye examinations were undertaken by three of the authors (JST, NP, RT). Distance visual acuity was

Table 1 Categories of visual impairment and blindness before and after refraction

WHO category	Level of visual acuity better eye	Presenting visual acuity in better eye			Best corrected visual acuity in better eye		
		No	%	95% CI	No	%	95% CI
No or mild impairment	6/18 or better	4	0.6	0.2 to 1.0	9	1.3	0.6 to 2.0
Moderate visual impairment	<6/18–6/60	26	3.7	1.1 to 6.3	44	6.3	3.1 to 9.5
Severe visual impairment	<6/60–3/60	20	2.8	0.8 to 4.9	22	3.1	1.3 to 4.9
Blind	<3/60	653	92.9	89.3 to 96.5	628	89.3	84.7 to 93.9
Total		703	100		703	100	

measured using a Snellen E chart, and near vision was assessed using figures equivalent to N18. The findings of simple tests of functional vision—that is, the ability to walk unaided around chairs set 2 metres apart, to recognise faces at a distance of 3 metres, and to recognise the shape of three 2 cm symbols at any near distance were also recorded. Visual fields were assessed by confrontation. Refraction and low vision aid assessment, if indicated, were performed by a qualified optometrist in all children able to perform tests of functional vision. The anterior segment was examined using a torch and loupe and/or handheld slit lamp. The posterior segment was examined by direct and indirect ophthalmoscopy, after dilating the pupil.

The WHO/PBL eye examination record for children with blindness and low vision was used to categorise the causes of blindness and to record findings, using the definitions in the coding instructions.[6][7] A major anatomical site and underlying cause was selected for each eye, and for the child. For each child, the need for optical, surgical, or medical interventions were recorded and the expected visual prognosis assessed. Children requiring further investigations and treatment were referred to the Rajendra Prasad Centre for Ophthalmic Sciences for follow up. Data were entered into a database in EPI-INFO 6 and analysed using STATA 6 statistical software. A report of the findings and recommendations was given to the principal of each school.

RESULTS

A total of 703 students less than or equal to 16 years age were examined in 13 schools for the blind in Delhi; 90.5% (588) of the children examined belonged to north Indian states of Delhi, Haryana, Uttar Pradesh, and others. Among the children examined, 61.5% (400) were males. A history of consanguineous marriage of the parents was recorded in only 0.6% (four) of cases. Additional disability was found in 2.5% (16) of cases only. The majority of surgical interventions had been for cataract in 5.2% (68) of children, glaucoma in 3.1% (40), and penetrating keratoplasties in 1.3% (17) of children.

Based on vision at initial examination, 2.8% were severely visually impaired and 92.9% of children were blind (Table 1). With best correction, 3.1% were severely visually impaired and 89.3% of children continued to be blind; 3.6% (25) of children improved by at least one category of blindness; 3.9%(28) of children were already wearing glasses at the time of examination. After refraction, 6.6% (47) of children had an improvement in visual acuity in the better eye with spectacles and were prescribed the same. Of the 124 (17.6%) children with functional low vision, 51 (41.1%) were able to read N-18 unaided or with distance spectacles and were not assessed for low vision devices (LVDs). Thirty children (24.1%) improved to N-18 with spectacle magnifiers, which were prescribed. The major anatomical sites of visual loss in children who benefited from LVDs were aphakia (14), uveal coloboma(5), optic atrophy(4), and others.

Data on causes were analysed for the 650 children who were SVI/BL after refraction (<6/60 in the better eye). The whole globe (27.4%), cornea (21.7%), and retina (15.1%) were found to be the most frequently affected sites of abnormality (Table 2). The globe appeared normal in three children with high pathological myopia and in two children with cortical blindness. The aetiological classification was based on the time of onset of the insult leading to visual loss, and the findings are shown in Table 3. In 56.5% (367 children) the underlying cause could not be determined; the abnormality had been present since birth in 42.3% (275 children), and cataract and glaucoma of unknown cause were responsible for blindness in 8.3% (54 children) and 4.9% (32 children), respectively. Prenatal factors (that is, hereditary factors, intrauterine conditions, and those present since birth) were identified in over half the children in the study (56.6%). Hereditary factors were identified in 13.4% (87) cases, in which there was a positive family history of another similarly affected individual or well recognised or proved genetic/chromosomal disorders according to WHO/PBL eye examination record coding instructions. Acquired conditions of childhood were responsible for visual loss in 28.0% of children, vitamin A deficiency being the single commonest cause (20.5%).

Table 2 Anatomical site of severe visual impairment and blindness in 650 children examined in 13 schools for the blind in Delhi

	No	No	%	%
Whole globe	178		27.4	
Microphthalmos		68		10.5
Anophthalmos		50		7.7
Phthisis		58		8.9
Others		2		0.3
Cornea	141		21.7	
Staphyloma		93		14.3
Scar		35		5.4
Others		13		2.0
Lens	71		10.9	
Cataract		35		5.4
Aphakia		29		4.5
Pseudophakia		6		0.9
Others		1		0.2
Retina	98		15.1	
Dystrophy		85		13.1
Others		13		2.0
Optic nerve	69		10.6	
Atrophy		58		8.9
Hypoplasia		10		1.5
Others		1		0.2
Uvea	57		8.8	
Coloboma		50		7.7
Others		6		0.9
Glaucoma	32		4.9	
Buphthalmos		32		4.9
Others	5		0.8	
High pathological myopia		3		0.5
Cortical blindness		2		0.3
Total	650	650	100	100

Table 3 Aetiological classification based on time of onset of visual loss of severe visual impairment and blindness in 650 children examined in 13 schools for the blind in Delhi

Aetiology	No	No	%	%
Hereditary factors	87		13.4	
Autosomal recessive		38		5.8
Autosomal dominant		10		1.5
Others		39		6.0
Intrauterine factors	6		0.9	
Rubella		3		0.5
Others		3		0.5
Perinatal factors	8		1.2	
ROP		3		0.5
Neonatal meningitis		3		0.5
Others		2		0.3
Childhood factors	182		28.0	
Vitamin A deficiency		133		20.5
Meningitis		13		2.0
Trauma		11		1.7
Others		25		3.8
Undetermined	367		56.5	
Cataract		54		8.3
Glaucoma		32		4.9
Abnormality since birth		275		42.3
Others		6		0.9
Total	650	650	100	100

Overall, 43.5% (283 children) had potentially avoidable cause of blindness: preventable causes in 28.0% (182 children), and treatable causes in 15.5% (101 children) (Table 4). Vitamin A deficiency was the major preventable cause of visual loss, and cataract and glaucoma were the main treatable causes.

In order to explore possible trends in the major causes of severe visual impairment and blindness over time, the data were analysed after dividing the children into three age groups 5–8 years, 9–12 years, and 13–16 years. In the 650 children analysed, 17.8% (116) were aged 5–8 years, 36.5% (237) were 9–12 years old, and 45.7% (297) were aged 13–16 years. Retinal disorders includes retinal dystrophy, albinism, retinal detachment, and retinopathy of prematurity. These were responsible for visual loss in 22.4% (26) in 5–8 year olds, 16.4% (39) in 9–12 year olds, and 11.1% (33) in 13–16 year olds (p <0.001, χ^2 test for trend) (Fig 1A). The proportion of children blind from corneal disorders was 16.3% (19), 22.7% (54), and 22.9% (68) in the same age groups (p = 0.36, χ^2 test for trend). There was no statistically significant trend in the proportion of children in the different age groups who were blind from dis-

Table 4 Avoidable causes of severe visual impairment and blindness among 650 children examined in 13 schools for the blind in Delhi

	No	% of total
Preventable		
Vitamin A deficiency/measles	139	21.4
TORCH/meningitis	22	3.4
Autosomal dominant	10	1.5
Trauma/harmful traditional eye remedies	11	1.7
Subtotal:	182	28.0
Treatable		
Cataract	54	8.3
Glaucoma	32	4.9
Uveitis	12	1.8
ROP	3	0.5
Subtotal:	101	15.5
Total avoidable	283	43.5
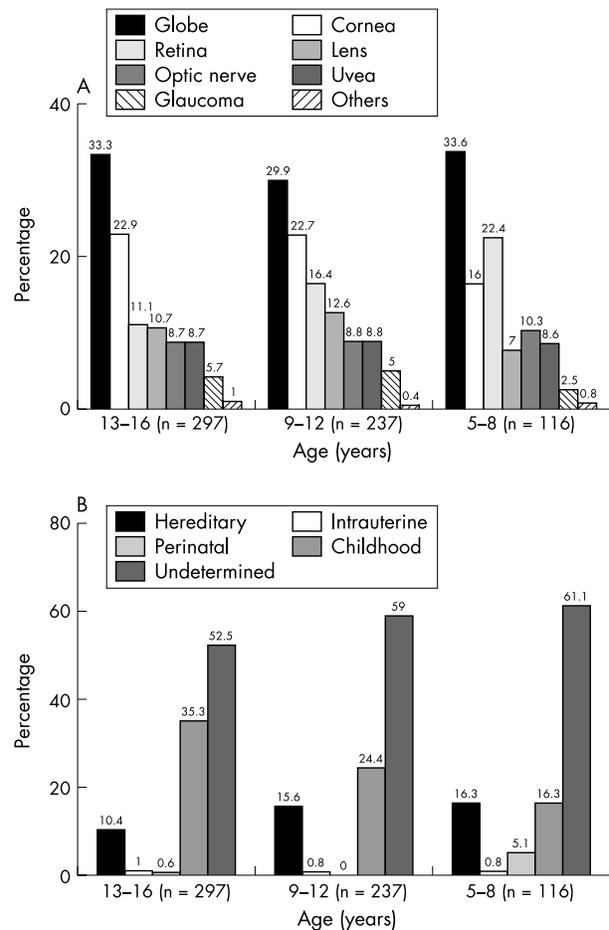
Figure 1 (A) Anatomical site of abnormality in children with severe visual impairment and blindness, by age group. (B) Aetiological categories of severe visual impairment and blindness, by age group.

orders of the lens. Study of aetiological factors showed that childhood disorders were responsible for 16.3% (19) in 5–8 year olds, 24.4% (58) in 9–12 year olds, and 35.3% (105) in 13–16 year olds (p <0.001, χ^2 test for trend) (Fig 1B). Within this, vitamin A deficiency was responsible for 12.5% in 5–8 year olds, 17.8% in 9–12 year olds, and 24.5% in 13–16 year olds (p =0.01, χ^2 test for trend). The proportion of children blind from hereditary disorders was 16.3% (19), 15.6% (37), and 10.4% (31) in the same age groups (p = 0.06, χ^2 test for trend). There was no statistically significant trend in the proportion of children in the different age groups who were blind from undetermined factors. In a multiple regression model, adjusting for sex, immunisation, and family history the association of age with retinal (p=0.004, χ^2 test for trend of odds) and childhood disorders (p<0.001, χ^2 test for trend of odds) persists. There was a statistically significant difference between age groups 5–8 years and 13–16 years in retinal (p=0.005) and childhood disorders (p=0.0001), though proportions at the 9–12 year age group did not differ significantly from the 5–8 years age group with regard to retinal (p=0.09) and childhood disorders (p=0.05).This could possibly reflect a transition period in the epidemiology of childhood blindness in India.

DISCUSSION

At least half and possibly up to three quarters of childhood blindness is avoidable. In order to develop control programmes to prevent childhood blindness it is necessary to identify important avoidable causes in each country and monitor the

Table 5 Comparison of anatomical and aetiological causes of SVI/BL in different studies

	Present study	India[5]	Sri Lanka[12]	China[14]	West Africa[13]	Czech Rep[16]
	No (%)	No (%)	No (%)	No (%)	No (%)	No (%)
Author (year)	Titiyal *et al* 2001	Rahi *et al* 1993	Eckstein *et al* 1995	Hornby *et al* 1999	Gilbert *et al* 1993	Blohme *et al* 2001
Anatomical						
Whole globe	178 (27.4)	334 (25.3)	81 (35.8)	288 (25.5)	24 (8.5)	25 (10.9)
Cornea	141 (21.7)	348 (26.4)	5 (2.2)	49 (4.4)	102 (35.9)	4 (1.8)
Lens	71 (10.9)	162 (12.3)	39 (17.3)	213 (18.8)	44 (15.5)	20 (8.7)
Retina	98 (15.1)	273 (20.7)	50 (22.1)	282 (24.9)	58 (20.4)	124 (54.2)
Aetiology						
Hereditary	87 (13.4)	303 (22.9)	79 (35)	347 (30.7)	60 (21.1)	21 (9.2)
Childhood	182 (28.0)	367 (27.9)	12 (5.3)	158 (14)	96 (33.8)	10 (4.4)
Undetermined	367 (56.5)	607 (46)	127 (56.2)	599 (52.9)	99 (34.9)	97 (44.3)
Total	650 (100)	1318 (100)	226 (100)	1131 (100)	284 (100)	229 (100)

changing patters of childhood SVI/BL in each country over time. It is estimated that 15 000 children attend residential schools for the blind in India and a further 5000 are in integrated education.[8] These children represent approximately 10% of the total number of blind children in India. Blind school studies have the advantage that a large number of children can be examined in a short time, are relatively inexpensive, can be done by a single observer, and provide an indication of relative importance of the different causes of blindness. However, they are subject to certain inherent biases: children less than 5 years of age, those with multiple disabilities, and those from lower socioeconomic groups or from rural communities are likely to be under-represented, as are causes in children who have died. Blind school studies have been undertaken in various countries using the standard WHO proforma and have found a varied spectrum of causes of blindness in children[9–16] (Table 5). In the present study, only 2.5% of children had an additional disability, which is very low compared to Western surveys, as children with multiple disabilities are often refused entry to blind schools in India and, therefore, causes of visual loss with other disabilities tend to be under-represented.

In the present study, congenital ocular anomalies (mainly microphthalmos, anophthalmos, and coloboma) accounted for 25.8% of SVI/BL. Congenital anomalies may be due to genetic diseases or intrauterine factors, but in majority the aetiology is unknown. The reason for the high proportion of anomalies in our study is not clear, but similar findings have been reported from other institution based and population based studies in India.[9 17] Corneal blindness was the second most common cause of SVI/BL (21.7%) and the major preventable cause identified. Although it is difficult to specifically ascertain the aetiology of corneal scarring several years after the original pathology, vitamin A deficiency appears to be the major cause as in the majority of children with corneal scarring, diarrhoea, or measles (which can precipitate acute vitamin A deficiency) preceded the onset of visual loss. Retinal causes, primarily retinal dystrophies, accounted for 15.1% of the cases, and disorders of the lens accounted for 10.9%. In this study 50% of children with disorders of the lens had unoperated cataract.

The importance of hereditary factors (13.4%) and childhood factors (28.0%) contrasts with the small contribution from perinatal and intrauterine factors. However, this study may underestimate the importance of both genetic and intrauterine factors, as in 42.3% of children the abnormality had been presented since birth but the aetiology could not be determined. The presence of a large proportion of children with visual loss of undetermined aetiology is consistent with results from other studies and reflects limited scope for investigation, and lack of examination of family members in many cases.

Overall, 43.5% of children were blind from potentially preventable or treatable conditions. Preventable causes included vitamin A deficiency, measles, trauma, autosomal dominant conditions, and TORCH infection. These findings suggest the importance of primary prevention—for example, high measles immunisation coverage, promotion of breast feeding, health and nutrition education, and continued programmes for the control of vitamin A deficiency through child survival programmes. Reduction in blindness due to genetic diseases will prove more challenging as there are few medical geneticists in India, and advice given will need to be sensitive to the complex social, economic, and cultural factors influencing marriage and child rearing, and the possible consequences of attributing "blame."

Treatable causes included cataract, glaucoma, and uveitis. There is a need to expand specialist paediatric ophthalmic services in India, and it has been recommended that there should be one well equipped child eye care centre for every 10 million total population.[2] In India this would translate to 100 centres throughout the country. There is a need for screening for early detection of cataract and glaucoma with appropriate referral to a tertiary care centre. It is important to begin to develop screening for retinopathy of prematurity as that is an increasing problem in countries with improving and expanding neonatal intensive care.

Comparison of causes of SVI/BL in different age groups needs to be interpreted cautiously, as the data are not population based and only a small proportion of blind children are in special education. Another factor to consider is the age at which children become blind from different disorders varies—that is, keratomalacia usually occurs during preschool years, whereas blindness from retinal dystrophies may not occur until later in childhood. Having said this, the data do seem to suggest that corneal blindness is a less important cause in younger children than in older children. If true, this may reflect a decline in the incidence of corneal scarring in response to rapid improvements in socioeconomic development experienced by many communities in India, particularly with respect to better water supplies and sanitation, improved measles immunisation coverage, and highly effective programmes for child spacing with many states reaching the replacement level of fertility.

In conclusion, the present study suggests changing trends in corneal blindness in north India. The continued presence of vitamin A deficiency related blindness is, however, a cause for concern as it is well documented that effective primary care interventions have tremendous potential to reduce the burden of corneal blindness. The accessibility and sociocultural acceptability of interventions for the control of vitamin A deficiency need to be carefully assessed. Short term interventions, like vitamin A supplementation, can lose momentum

over time and are not sustainable in the long term. Dietary modifications and ensuring adequate availability of vitamin A rich foods need to be pursued vigorously. The present study highlights that emphasis needs to be laid on the provision of low vision services to visually impaired children in schools for the blind so that they can maximise their residual vision and improve their quality of life.

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REFERENCES

1 **World Health Organization**. *Global initiative for the elimination of avoidable blindness.* WHO/PBL/97.61. Geneva: WHO, 1997.
2 **World Health Organization**. *Preventing blindness in children.* Report of a WHO/IAPB scientific meeting..WHO/PBL/00.71. Geneva: WHO, 2000.
3 **Anon**. Blindness in the world. *Surv Ophthalmol* 2000;**45**(Suppl):s21–31.
4 **Census of India 2001**. India: Registrar General and Census Commissioner, 2001.
5 **Rahi JS**, Sripathi S, Gilbert CE, *et al*. Childhood blindness in India:causes in 1318 blind school studies in nine states. *Eye* 1995;**9**:545–50.
6 **Gilbert CE**, Foster A, Thylefors B, *et al*. Childhood blindness—a new form for recording causes of visual loss in children. *Bull World Health Organ* 1993;**71**:485–89.
7 **ICEH**. Coding Instructions. *WHO/PBL eye examination record for children with blindness and low vision.* London: ICEH.
8 **Rahi JS**, Sripathi S, Gilbert CE, *et al*. Childhood blindness due to vitamin A deficiency in India; regional variations. *Arch Dis Child* 1995;**72**:330–3.
9 **Hornby S**, Adolph S, Gothwal V, *et al*. Evaluation of children in six blind schools of Andhra Pradesh. *Indian J Ophthalmol* 2000;**48**:195–200.
10 **Schwabe L**, Kagame K. Blindness in Africa: Zimbabwe schools for the blind survey. *Br J Ophthalmol* 1993;**77**:410–12.
11 **Goggin M**, Keefe M. Childhood blindness in Republic of Ireland: a national survey. *Br J Ophthalmol* 1991;**75**:425–9.
12 **Eckstein MB**, Foster A, Gilbert CE, *et al*. Causes of blindness in Sri Lanka: results from children attending six schools for the blind. *Br J Ophthalmol* 1995;**79**:633–6.
13 **Gilbert CE**, Canovas R, Hagan M, *et al*. Causes of childhood blindness: results from West Africa, South India and Chile. *Eye* 1993;**7**:184–8
14 **Hornby S**, Foster A, Gilbert CE, *et al*. Causes of blindness in People's Republic of China: results from 1131 blind school students in 18 provinces. *Br J Ophthalmol* 1999;**83**:929–32.
15 **Waddell KM**. Childhood blindness and low vision in Uganda. *Eye* 1998;**12**:184–92.
16 **Kocur I**, Kuchynka P, Rodny S, *et al*. Causes of severe visual impairment and blindness in children attending schools for the visually handicapped in the Czech Republic. *Br J Ophthalmol* 2001;**85**:1149–52.
17 **Dandona L**, Williams JD, Williams BC, *et al*. Population-based assessment of childhood blindness in India. *Arch Ophthalmol* 1998;**116**:545–6.