WORLD VIEW

Changing pattern of childhood blindness in Maharashtra, India

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Aim: To determine the causes of severe visual impairment and blindness in children in schools for the blind in Maharashtra, India.

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Methods: Children aged <16 years with a visual acuity of <6/60 in the better eye, attending 35 schools for the blind were examined between 2002 and 2005, and causes were classified using the World Health Organization's system.

Results: 1985 students were examined, 1778 of whom fulfilled the eligibility criteria. The major causes of visual loss were congenital anomalies (microphthalmos or anophthalmos; 735, 41.3%), corneal conditions (mainly scarring; 395, 22.2%), cataract or aphakia (n = 107, 6%), and retinal disorders (mainly dystrophies; n = 199, 11.2%). More than one third of children (34.5%) were blind from conditions which could have been prevented or treated, 139 of whom were referred for surgery. Low vision devices improved near-acuity in 79 (4.4%) children, and 72 (4%) benefited from refraction. No variation in causes by sex or region was observed.

Conclusions: Congenital anomalies accounted for 41% of blindness, which is higher than in a similar study conducted 10 years ago. Corneal scarring seems to be declining in importance, low vision and optical services need to be improved, and research is needed to determine the aetiology of congenital anomalies.

The control of childhood blindness is a priority of "VISION2020—The Right to Sight".¹ This global initiative aims to eliminate avoidable blindness by the year 2020, and the first phase focuses on the implementation of cost-effective strategies. Although blindness in children is relatively uncommon, it is a priority of VISION2020, as severe visual loss in early childhood adversely affects development, mobility, education, and social and employment opportunities. The prevalence of blindness in children ranges from approximately 0.3/1000 (of total population) in affluent countries to 1.5/1000 in the poorest²; but owing to demographic differences, the actual number of blind children per million total population ranges from approximately 60 in affluent societies to 600 in the poorest communities.

Epidemiological data on blindness in children in India are incomplete, but population-based studies have estimated the prevalence as follows: 0.65/1000 (95% confidence interval 0.15 to 1.15/1000) in children aged 0–15 years in urban and rural Andhra Pradesh³; 1.25/1000 in children aged 5–15 years in rural Andhra Pradesh⁴; and 0.53/1000 in children aged 5–15 years in Delhi.⁵ These figures are not directly comparable, as different definitions of blindness have been used, and the samples are of different ages. Overall, the prevalence in India is estimated to be 0.81/1000 children,⁴ ranging from 0.3/1000 in well-developed states (eg, Kerala) to 1.5/1000 children in the poorest. These figures have been derived using the association between the prevalence of blindness in children and mortality in children aged <5 years (as a proxy for socioeconomic development and healthcare delivery).⁶

Reliable population-based data on the causes of blindness in children are difficult to obtain, particularly in developing countries. Examination of children enrolled in special education is one source, but bias is inherent in all facility-based studies. Advantages of school studies are that a large number of children can be examined quickly by a few examiners. Over the past 10 years, the World Health Organization's classification system⁷ has been increasingly used, which allows data to be compared.

A study on about 1300 children in nine Indian states undertaken in 1993, showed corneal scaring (mainly from vitamin A deficiency (VAD)) to be the single most common (26.4%) cause of blindness, followed by congenital anomalies (mainly anophthalmos and microphthalmos; 20.7%) and retinal diseases (19.3%).⁸ The major causes varied from region to region, with corneal scarring being less important in children in schools serving urban areas.⁸ The study only included 157 children from two schools in Maharashtra.

India is developing rapidly, but improvements are not taking place evenly across the country. Maharashtra is on the western coast and has varying ecology and climate, with a narrow, wet, coastal strip (Konkan, includes the capital Mumbai), a mountainous area, a prosperous, well-irrigated region (West Maharashtra, with Pune as the largest city), a forested, tribal area (Vidarbha, with Nagpur as the largest city), and dry, arid regions in the north (Khandesh) and centre (Marathwada, with Aurangabad as the largest city). Maharashtra is India's second largest and second most populated state (102 million), with an adult literacy rate of 77%.9 It is among the more prosperous states (per capita income of US \$544). The past two decades have seen nearly universal immunisation, increased school attendance, and improved eye care and child care facilities. The infant mortality was 45/1000 live births in 2001 compared with the national average of 64/1000.9

This study was undertaken to determine the causes of blindness in all children attending schools for the blind in Maharashtra.

METHODS

Children attending all special schools for blind children in Maharashtra were examined between 2002 and 2005. Schools were contacted through the National Association for the Blind, Mumbai, India, the Poona Blind Men's Association, Pune,

Abbreviations: ROP, retinopathy of prematurity; VAD, vitamin A deficiency

 Table 1
 World Health Organization categories of visual loss in 1795 children attending 35 schools for the blind in Maharashtra, India

	West Maharashtra	Vidarbha	Marathwada	Khandesh	Whole of Maharashtra
Category of visual loss	n (%)	n (%)	n (%)	n (%)	n (%)
Normal vision: ≥6/18	1 (0.2)	3 (0.6)	2 (0.4)	0 (0)	6 (0.3)
Visual impairment: 6/24–6/60	3 (0.5)	4 (0.8)	2 (0.4)	2 (0.9)	11 (0.6)
Severe visual impairment: <6/60-3/60	25 (4.2)	19 (3.8)	10 (2.0)	12 (5.5)	66 (3.7)
Blind: <3/60	561 (95.1)	473 (94.8)	474 (97.1)	204 (93.6)	1712 (95.4)
Total	590 (100)	499 (100)	488 (100)	218 (100)	1795 (100)

India, and other agencies. All the blind schools except four are run by non-governmental organisations, and none admit children with additional disabilities.

Relevant information was collected from class teachers and children. A brief history of the family, place of residence and whether the parent's marriage was consanguineous were recorded. Information on additional disabilities (eg, mental retardation, physical handicap, epilepsy or deafness) was obtained from children's records. A detailed eye examination was performed by a team of optometrists and ophthalmologists. Distance visual acuity was measured using a Snellen E chart, and near-vision was assessed using figures equivalent to N18. Simple tests of functional vision were undertaken. Intraocular pressures were not measured, and visual fields were assessed by confrontation. Children were refracted, and assessed for lowvision devices, if indicated.¹⁰ Anterior segments were examined using a torch and loupe or a handheld slit lamp, and posterior segments were examined by direct and indirect ophthalmoscopy after dilating the pupils.

The World Health Organization classification system for children was used to categorise causes using definitions in the coding instructions.⁷ One major anatomical site and underlying cause were selected for each eye and for each child. The need for optical, surgical or medical interventions was recorded and the visual prognosis assessed. Children requiring further investigations and treatment were referred to the H.V. Desai Eye Hospital, Pune, India. Data were entered and analysed using EPI-INFO 6 (World Health Organization). A report of the

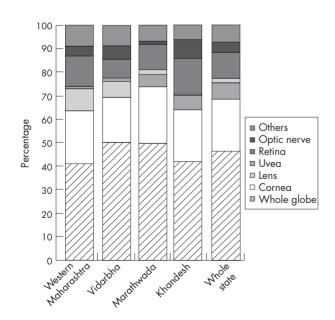


Figure 1 Causes of severe visual impairment and blindness.

findings and recommendations were given to the principal of each school.

RESULTS

Study population

A total of 35 residential schools were identified and visited (11 in western Maharashtra, 10 in Vidarbha, 10 in Marathwada and 4 in Khandesh, listed in appendix) in which 1985 children were enrolled, 1795 of whom were aged <16 years. About half were boys (1126/1985; 56%), and this sex difference was found in each region (west Maharashtra, 54.6%; Vidarbha, 52.9%; Marathwada, 74.0%; Khandesh, 67.9%). The youngest child was 2 years old.

The vast majority of children were blind (visual acuity of <3/ 60 in the better eye; 1712/1795; 95.4%), and a further 66 (3.4%) were severely visually impaired (visual acuity <6/60 to 3/60) (table 1). Data presented in this paper are for children aged <16 years who were blind or severely visually impaired (n = 1778). Almost three quarters (73.3%) gave a history of being blind since birth; only 2.3% lost vision during infancy, whereas 13.4% became blind during childhood. Only 18% of children reported another similarly affected family member, and 10% knew their parents were related by birth. We found no difference in rates of consanguinity between regions. More than half of the children (58%) could see well enough to walk about unaided, 25% could recognise faces and 13% could see shapes.

Causes of severe visual impairment and blindness

In all 823 (46.3%) children were blind from disorders of the whole globe, microphthalmos being responsible for 30.7% and anophthalmos for 10.4% (fig 1). Corneal causes (including phthisis bulbi) were recorded in 395 (22.2%) children. Disorders of the lens were found in 107 (6.0%) children, 80 of whom had unoperated cataracts. Of these, 16 children had dense amblyopia or had had complicated surgery, and 54 children with pseudophakia/aphakia had visual loss due to coexisting retinal pathology. Retinal factors accounted for 199 (11.2%) cases, the majority being retinal dystrophies. No child was blind from retinopathy of prematurity (ROP). Optic nerve lesions were diagnosed in 81 (4.6%) children and uveal conditions (mainly uveitis and colobomas) in 27 (1.5%) children. We found no major differences in causes between regions: in particular, corneal scarring was not more common in the poorer tribal belts of Khandesh (11.6%) and Vidarbha (14.2%) compared with the prosperous western Maharashtra (12.5%)

In more than two thirds (69.2%) of children, an underlying cause could not be determined; most children were blind from prenatal factors (ie, anophthalmos, microphthalmos, cataract and glaucoma). In all, 13.7% of children were blind because of hereditary factors, 11.1% of children had acquired causes of blindness (from trauma, corneal infections or VAD) and 4.6%

Causes	West Maharashtra	Vidarbha	Marathwada	Khandesh	Whole of Maharashtra
Preventable					
Cornea	73	56	73	30	232
Phthisis	59	39	47	18	163
Subtotal	132 (22.5)	95 (19.3)	120 (24.8)	48 (22.2)	395 (22.2)
Treatable					
Cataract	45	28	22	12	107
Glaucoma	17	6	6	3	32
Amblyopia	29	18	9	9	65
Uveitis	5	5	4	1	15
Subtotal	96 (16.4)	57 (11.6)	41 (8.4)	25 (11.5)	219 (12.3)
Total avoidable	228/586 (38.9)	152/492 (30.9)	161/484 (33.2)	73/216 (33.7)	614/1778 (34.5)

were blind from intrauterine factors. We found no differences in underlying cause by sex or by region.

Causes in different age groups

Corneal causes seem to have declined in importance over time, as 24.8% of children aged 11–16 years were blind from corneal scarring and phthisis bulbi compared with 19.6% of children aged 7–10 years and 10.7% of children aged <7 years.

Avoidable causes

Preventable causes of blindness, such as corneal scarring and phthisis, mainly attributed to measles, VAD, trauma and harmful traditional medicines, accounted for 22.2% of all causes, whereas treatable causes were found in 219 (12.3%) children. Thus, 614 children (34.5%) had avoidable causes of blindness (table 2). In all, 139 children were referred for evaluation and surgery (eg, cataract extraction, intraocular lens implantation, keratoplasty); the visual acuity could be improved by refraction in 72 children and 79 would benefit from low-vision devices. A change of school was recommended for 63 children.

Comparison with the 1993 study

Some differences between the 1993 study and this study are apparent, in that disorders of the lens (cataract and aphakia) seem to be less important now, whereas microphthalmos and anophthalmos have increased in importance from 17.2% to 41.3% (table 3).

DISCUSSION

Studies on children receiving special education have limitations, as children attending special schools may be different from blind children not attending school. In particular, causes associated with additional handicaps, those primarily affecting children from poor remote communities, are likely to be underrepresented, as are causes associated with a high mortality. However, where data from children in special education have

	1993 n (%)	2005 n (%)
Cornea	32 (20.4)	395 (22.2)
Lens	20 (12.7)	107 (6.0)
Retina	22 (13.8)	199 (11.2)
Anophthalmos/microphthalmos	27 (17.2)	735 (41.3)
Other causes	51 (35.9)	342 (19.3)
Total	152 (100)	1778 (100)

been compared with data from community samples the findings have generally been comparable.¹¹

In our study, the observed pattern of causes is intermediate between that seen in industrialised countries and the poorest developing nations. In our study, older children were more likely to be blind from corneal scarring than younger children, which suggests that measles and VAD may be declining in importance. A similar change was documented in Saudi Arabia, where socio-economic development has led to genetic diseases predominating over infectious causes.¹² Corneal blindness was also reported to be less important in younger children than in older children in a recent blind school study in Delhi, India.¹³ The lower incidence of corneal blindness, particularly in Asia where mortality of children aged <5 years is declining, is almost certainly due to better primary healthcare, higher measles immunisation coverage and child survival initiatives that include control of VAD.

Despite marked differences in ecology, climate and prosperity, we found no differences in causes between different regions within the state. This is in contrast with a study undertaken in schools for blind in Andhra Pradesh, where regional differences were observed.¹⁴ In our study there was a preponderance of boys, which is a common finding in facility based studies in developing countries, where cultural factors and economic constraints may lead to sex discrimination.

The most striking finding of our study is the very high proportion of blindness due to microphthalmos and anophthalmos. This has been a common finding in studies on blind chidren in India, including population based-studies on children in community-based rehabilitation,8 13-15 but the reasons are not known as most causes of blindness are sporadic.¹⁶ Known causes include chromosomal abnormalities (<10% of cases in some series)¹⁷ and some can be familial, with autosomal dominant, recessive or X-linked recessive pedigrees being reported. As families with more than one affected individual are uncommon, linkage analysis is usually not possible.18 Several regulatory genes important in ocular development have been implicated in the aetiology, including SHH, PAX6, PAX2 and CHX10,¹⁹ as have environmental factors (ie, intrauterine infections, use of pharmaceutical and recreational drugs, alcohol, hyperthermia and maternal hyothyroidism).20 21 Exposure to pesticides has also been postulated,²² which might be relevant in this highly agricultural area where fertilizers and pesticides are used intensively. However, in all series, including a large case series from Andra Pradesh,23 most cases are sporadic and of unknown cause. One hypothesis is that microphthalmos, anophthalmos and coloboma are due to interactions between genes controlling retinoic acid signalling and maternal VAD during early fetal development²⁴-a mechanism similar to folate deficiency and spina bifida-with supportive evidence coming from animal experiments, and epidemiological and laboratory studies. If defects in genes controlling retinoic acid signaling occur at a high rate in the Indian population, where maternal VAD and consanguinity are common, this may explain why anomalies are such an important cause of blindness in Indian children.

Public health approaches to preventing congenital anomalies are limited to health education concerning exposure to known risk factors during pregnancy and rubella immunisation. However, rubella immunisation of infants is not without risk, having the potential to increase the number of babies born with congenital rubella if high coverage is not maintained.²⁵ In India, rubella immunisation is available only privately, with low levels of uptake. Children with microphthalmos can often benefit from refraction and low-vision services^{10 26} as has also been shown in this study.

In our study, about one third of children were blind from potentially avoidable causes. No children was blind from ROP, which is reaching epidemic proportions in many middle income countries, and which is being increasingly reported from other cities in India.^{27 28} There are several explanations: children blind from ROP often have other disabilities, and may not attend school or may have died, and most children in our study were aged >10 years, and ROP may be a cause in younger children. Given the expanding economy in Maharashta, ROP blindness will probably become another avoidable cause unless screening programmes are implemented as services for premature babies expand.

Preventable causes of blindness can be reduced at the primary level of service delivery, whereas treatable causes require specialised, paediatric ophthalmology units, systems for early identification and referral, and increased public awareness. A comprehensive approach is therefore needed, including provision for children with low vision. Maharashtra needs at least five tertiary child eye care centres (one for every 20 million people), but currently has only one (the H.V. Desai Eye Hospital, Pune, India), which was established with support from ORBIS International in 2004.

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APPENDIX

Names of blind schools, Maharashtra, India Western Maharashtra:-

- 1. Bhiruratan Damani Andha Shala Nivasi, Solapur
- 2. Rajiv Gandhi Memorial School for the Blind, Solapur
- 3. Lion's Club Pandharpur Sanchalit Sarkarmanya Andh Vikas Sanstha, Pandharpur, Solapur
- 4. Prabodhan Andh Vidyalay, Koregaon, Satara
- Shri Sadguru Dhondiraj Nivasi Andh Vidyalay, Palus, 5. Sangli
- 6. Dyan Prabodhan Bhavan Sanchalit Andhashala, Miraj-Tikati, Kolhapur
- N.A.B Nivasi Andha Vidyalay, Miraj, Sangali 7.
- 8. P.R Lunkad Blind School, Bhosari, Pune
- Jagruti School For Blind Girls, Alandi, Pune 9
- 10. Poona School & Home For Blind Boys, Pune
- Poona School & Home For Blind Girls, Pune 11.

Vidarbha:-

- 1. Yashwant Andh Vidyalay, Amravati
- 2. Apang Kalyan & Punarvasan Sanstha, Buldhana
- 3. Kurvey's New Model High School & Junior College, Nagpur
- 4. The Blind Boys' Institute, Nagpur
- 5. Narendra Bhivapurkar Andha Vidyalay, Amravati
- 6. Dyanjyoti Andha Vidyalay, Dhatarkheda, Nagpur
- 7. Kanubai Vohra Andha Vidyalay, Akola
- 8. NA Vidyalay, Chikhaldara, Amravati
- 9. Anand Blind School, Warora, Chandrapur
- 10. Shri Govindrao Bijure Andha Vidyalay, Daryapur, Amravati

Marathwada:-

- 1. School for the Blind Bodhani, Kinwat, Nanded
- 2. Niwasi Andha Vidyalay, Vasarani, Nanded

- 3. Andha Vidyalay, Deglur, Nanded
- 4. Shri Guru Ganesh Drishtihin Vidyalay, Jalna
- 5. Lt Gangabai Madhavrao Borole Nivasi Andha Vidyalay, Nilanga, Latur
- 6. Matoshri Gangadevi Dewda Niwasi Andha Mulanche Vidyalay, Hingoli
- 7. M.A.B Andha Vidyalay, Udgir
- 8. Taramati Bafna Blind School, Aurangabad
- 9. Pradnyachakshu Niwasi Andha Vidyalay, Beed
- 10. Shaskiya Andha Vidyalay, Latur

Khandesh:-

- 1. Malegaon Andh Sikshan & Prasikshan Sanstha, Malegaon, Nashik
- 2. Girls' School For Blind, Dhule
- 3. Andh Mulanchi Shala, Dhule
- 4. Rashtriya Prasar Mandal Sanchalit Andh Vidyalaya, Chalisgaon, Jalgaon

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