

Childhood blindness and severe visual impairment in Malaysia: a nationwide study

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Abstract

Aim To determine the causes of childhood blindness and severe visual impairment (BL/SVI) in schools for the blind in Malaysia. **Methods** All children ≤ 15 years attending 24 schools for the blind throughout the country were examined using the WHO Prevention of Blindness Programme (WHO/PBL) eye examination record for children, and visual loss was classified according to the International Classification of Disease (ICD). **Results** In all, 469 children were examined, of whom 448 (95.6%) had BL/SVI. The major causes of visual loss were retinal disorders ($n = 148$, 33%; mainly retinopathy of prematurity ($n = 78$, 17.4%)), cataract/pseudophakia/aphakia ($n = 77$, 17.2%), and anomalies affecting the whole globe. ($n = 86$, 19.2%). The major underlying etiology was undetermined ($n = 193$, 43.1%), followed by hereditary factors, 21.7% (mainly retinal dystrophies), and perinatal factors, 20.5%. More than 34 (7.6%) cases were considered potentially preventable and 192 (42.9%) potentially treatable.

Conclusion Diseases of the retina are the major cause of visual impairment, with retinopathy of prematurity being an important avoidable cause. This reflects expansion of neonatal services in Malaysia, and improved survival of very low birth weight and preterm babies. Lens-related causes of visual impairment reflect the need to further improve pediatric ophthalmology services in Malaysia. *Eye* (2011) 25, 436–442; doi:10.1038/eye.2011.19; published online 25 February 2011

Keywords: childhood blindness; severe visual impairment; Malaysia; retinopathy of prematurity; WHO prevention of blindness programme

Introduction

Childhood blindness/severe visual impairment (BL/SVI) arises from a variety of diseases or insults that vary from location to location. Many conditions need early detection and prevention to prevent long-term visual loss from amblyopia. However, obtaining reliable data on causes of childhood blindness is difficult and many of the methods are subjected to inherent biases. In 1999, the World Health Organization (WHO) launched a program (VISION 2020: the Right to Sight)¹ to combat avoidable blindness in children as one of its priority. Globally, there are 1.4 million blind children and nearly half are avoidable.¹ The prevalence of blindness is related to the socioeconomic status of the country, ranging from an estimated 3/10 000 in industrialized countries to 15/10 000 in poorer nations.² In order to standardize data on the causes of blindness in children, the International Centre for Eye Health (ICEH) in collaboration with WHO developed a classification system with standard definitions and methodology.³ Data on the anatomical site of abnormality and underlying etiology of visual loss can now be compared between different studies.

Malaysia consists of two geographically distinct areas, West Malaysia (Peninsular Malaysia), and East Malaysia (located on the island of Borneo), with a total of 14 states. It is a country with multiple ethnicities comprising Malays (58%), Chinese (24%), Indians (8%), and other indigenous groups (10%). The total population of Malaysia in 2007 was estimated at 27.19 million, 28.7% of whom were children < 15 years ($\sim 7\,800\,000$), and the infant mortality rate (IMR) was 62/10 000 live births.⁴ In 2005, the under-five mortality rate was 12/1000 live births. The available evidence suggests that the prevalence of blindness in children is associated with under-five mortality rate. Using this

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assumption, the prevalence of blindness in children in Malaysia is likely to be 3/10 000 children.⁵ This means that in Malaysia there are ~2300 blind children, almost 2000 of whom will be of school-going age. Information on the causes of childhood blindness in Malaysia is incomplete, as only one study of children attending six schools has been undertaken in 1997 by Reddy *et al*.⁶ The Ministry of Health is the main provider of health care in Malaysia along with an active private sector. The current low IMR reflects the overall improvement of health care in Malaysia. However, the distribution of skilled specialists is unequal throughout Malaysia and highly trained specialists and equipment are usually available only in large cities. Currently, there are ~350 registered ophthalmologists, with 18 fellowship-trained pediatric ophthalmologists, half of them residing in large cities. The Malaysian government has plans to improve health care by refurbishment of existing hospitals, building fully equipped new hospitals, expansion of the number of polyclinics, and training more medical personnel that would invariably lead to an overall increase in eye-care standards.

There are 8 residential schools and 24 integrated schools for visually impaired children in Malaysia. Normally, children begin schooling at the age of 7 but in special schools, the children are being enrolled at the age of 6 years.

Materials and methods

This is a cross-sectional study of children with BL/SVI in blind schools throughout Malaysia ($n = 469$). A total of 32 schools for visually impaired children are available in Malaysia. In this study, only 7 residential and 17 integrated schools had children ≤ 15 years of age and we used these in the study. Previous approvals for data collection from the Ministry of Education of Malaysia, the Department of Special Education, and the medical ethics committee of the University of Malaya Medical Centre were obtained. Data were collected between January 2007 and December 2007. Detailed examinations were performed by a team (resident trainee ophthalmologist, optometrist, and a fellowship-trained consultant pediatric ophthalmologist). Relevant information were gathered from the class teacher, parents (whenever possible), medical records, and finally the children. Visual acuity assessment using an ETDRS chart and refraction was performed by a trained optometrist in children who were able to walk unaided, recognize face, or make social contact. This is functional vision. Anterior segment was examined with a portable slit lamp, and posterior segment examined with indirect ophthalmoscope after pupil dilatation. Final diagnosis on the cause of visual impairment was made by the

consultant pediatric ophthalmologist for all. The WHO classification system for children was used to categorize causes using definitions in the coding instructions.³ When two or more anatomical sites were responsible for visual impairment, the major site was selected; or if two or more sites contributed to visual impairment equally, the most treatable condition was selected. Etiological classification was divided into five categories depending on the time of onset of the condition. The need for optical, medical, and surgical aid was assessed and appropriate referrals were made to the hospital. Data summary was obtained using the Childhood Blindness Software version 1.2.75.⁷ The χ^2 tests for testing the null hypothesis of homogeneity of proportions of ocular illness categories between different school systems (residential and integrated), age groups, and geographical location (East and West Malaysia) were carried out using the R statistical computing environment (version 2.9.1).⁸

Results

A total of 469 children were examined, 250 from residential schools and 219 from integrated schools. Residential schools are schools with boarding facility and cater for children with BL/SVI only. Integrated schools enroll students who are able to cope with mainstream learning and follow verbal instruction.⁹ The data presented in this paper are for children ≤ 15 years who were severely visually impaired and blind ($n = 448$). A majority of the children were Malays (69%) followed by Chinese (16%), Indians (7%), and other ethnic groups (8%). More than half were boys ($n = 267$, 57%). There were 59 children (13%) with additional disability such as hearing loss, physical handicap, and being mentally challenged. The history of blindness since birth was present in 26%, whereas 22% lost vision in the first year of life. Similarly affected family members were seen in 21% of the children almost similar to a study from India.¹⁰ The majority of them ($n = 323$, 68.9%) were blind (best corrected visual acuity (BCVA) in the better eye of $< 3/60$). No statistical difference in visual impairment categories was observed between the two education systems ($P = 0.06$, 2 d.f.; Table 1). The anatomical causes of BL/SVI are shown in Table 2 and the underlying etiology, which uses the time of onset of the condition leading to visual loss, is presented in Table 3.

Retinal causes were responsible for BL/SVI in 148 children (33%), out of which retinopathy of prematurity (ROP) contributed as the major cause in 78 (17.4%) children. Retinal dystrophies were diagnosed in 46 (10.3%), retinoblastoma in 13 (2.9%), albinism in 2 (0.4%), and other retinal disorders including retinal detachment in 9 (2%) of these children. Disorders of the lens

Table 1 WHO categories of visual loss, using best corrected visual acuity (BCVA)

WHO category	Vision in better eye	Residential schools		Integrated schools		Total	
		N	%	N	%	N	%
No impairment	6/18 or better	0	0.0	1	0.5	1	0.2
Visual impairment	<6/18–6/60	9	3.6	11	5.0	20	4.3
Severe visual impairment	<6/60–3/60	57	22.8	68	31.1	125	26.7
Blind	<3/60–NPL	184	73.6	139	63.5	323	68.9
Total		250	100	219	100	469	100

P = 0.06.

Table 2 Anatomical site of abnormality leading to SVI/BL

Site of abnormality	Residential school		Integrated school		Total	
	N	%	N	%	N	%
Retina	83	36.6	65	29.4	148	33.0
Whole globe	33	14.5	53	24.0	86	19.2
Lens	40	17.6	37	16.7	77	17.2
Other	29	12.8	13	5.9	42	9.4
Cornea	16	7.0	22	10.0	38	8.5
Optic nerve	13	5.7	21	9.5	34	7.6
Uvea	13	5.7	10	4.5	23	5.1
Total	227	100	221	100	448	100

P = 0.001.

Table 3 Etiology of BL/SVI by age group

WHO category	6–10 years (P = 0.75)				11–15 years (P = 0.4)				Total	
	Residential		Integrated		Residential		Integrated		N	%
	N	%	N	%	N	%	N	%		
Unknown	44	38.9	27	46.6	54	42.2	68	45.6	193	43.1
Hereditary	22	19.5	15	25.9	29	22.7	31	20.8	97	21.7
Perinatal	35	31.0	10	17.2	25	19.5	22	14.8	92	20.5
Childhood	6	5.3	3	5.2	17	13.3	22	14.8	48	10.7
Intrauterine	6	5.3	3	5.2	3	2.3	6	4.0	18	4.0
Total	113	100	58	100	128	100	149	100	448	100

accounted for 77 (17.2%) children where amblyopia was the main cause of visual loss in 51 (11.4%) who had undergone surgery with or without intraocular lens. Also, 23 (5.1%) had cataract *in situ*, whereas 3 (0.7%) had subluxated lens. Conditions affecting the whole globe were seen in 86 (19.2%) of children with BL/SVI (microphthalmos 40 (8.9%), glaucoma/buphthalmos 34 (7.6%), and anophthalmos 9 (2.0%)). Three (0.7%) of the children had undergone enucleation for ocular tumor.

Causes relating to optic nerve and cerebral cortex were 34 (7.6%) and 11 (2.5%), respectively. Corneal diseases (phthisis bulbi, traumatic scarring, Steven–Johnson Syndrome, and dystrophy) were present in 38 (8.5%) children. Uveal disorders were identified in

23 children (5%). Dense amblyopia due to high refractive error and idiopathic nystagmus was seen in 42 children (9.4%). The causes of visual loss were remarkably similar among children in both types of education. There is statistically significant difference in the anatomical site of abnormality between residential and integrated schools (χ^2 test result: P-value = 0.001, d.f. = 7).

Etiology of visual impairment

The etiology could not be determined in 193 children (43.1%) of whom 55 (12.3%) had cataract, 34 (7.6%) glaucoma/buphthalmos, 13 (2.5%) retinoblastoma, disorders presumed to be prenatal in onset (microphthalmos and anophthalmos) in 42 (9.4%) children, and other causes (sporadic/nonfamilial) that could not be definitely classified in 49 (11%) children (Table 3). No statistically significant difference for the WHO categories between residential and integrated schools was detected in both age groups (6–10 years old: P-value = 0.75, d.f. = 4; 11–15 years old: P-value = 0.4, d.f. = 4). In addition, we did not find statistically significant difference for WHO categories between the two school system (Fisher’s exact test: residential schools P-value = 0.06; integrated schools P-value = 0.37).

In all, 97 children (21.7%) were blind from hereditary causes, mainly retinal dystrophies, albinism, Stargardt’s disease, and corneal dystrophies. Disorders related to perinatal and neonatal period were seen in 92 (20.5%) children. Of the 78 children with ROP, 35 children (20.5%) were between 6 and 10 years old and 43 children (15.5%) were between 11 and 15 years of age. Cerebral hypoxia resulting in brain damage was seen in 12 (2.6%) children and ophthalmia neonatorum in 2 (0.5%) children. Childhood factors were noted in 48 (10.7%) children (neoplasm, trauma, symblepheron, corneal scarring, and exposure keratopathy). Diseases acquired during intrauterine period such as toxoplasmosis and rubella was uncommon (18 children, 4%).

Avoidable causes Overall, 50.5% (226) cases in this study had avoidable causes of visual loss. The preventable causes were because of adverse drug reactions, trauma,

and infection. Lens disorders and ROP were the most common treatable conditions. A majority of them were in residential schools as they had very poor vision and could not cope with mainstream learning. Statistical significance exists between residential and integrated schools for causes of BL/SVI (Table 4; χ^2 test-statistic = 19, $P = 0.001$, d.f. = 4). A higher proportion of children in residential had avoidable causes than children attending integrated education (57.7 vs 43%).

Comparison between East and West Malaysia East Malaysia comprises the states of Sabah and Sarawak on the island of Borneo. Although it is a larger area than West Malaysia, it comprises a smaller population but with a larger of indigenous tribes living in the jungle with dubious links to health and educational facilities. In East Malaysia, of the 64 children enrolled, 57 (89%) had BL/SVI. There is statistically significant difference between East and West Malaysia for both types of schools in terms of visual loss distribution (χ^2 test-statistic = 13; $P = 0.01$, d.f. = 4). The main difference is found in the proportion of pupils in the

categories of no impairment or visual impairment in the integrated schools (53% of 13), which is ~9% in East Malaysia and 3% in West Malaysia (Table 5). The rest cannot be commented on as the cell counts were too low for analysis.

Need for services

Visual acuity could be improved by refraction in 12 children, and 52 required a change of spectacle prescription. Referral for further evaluation and surgery was recommended to the school principals for another 32 children.

Discussion

Data collected by examining children in schools for the blind are subjected to selection bias but this source of data can provide valuable information on the cause of childhood blindness in a country. An advantage is that many children can be examined by a team using a standard methodology, but interpretation of results should be done with caution because the children in the

Table 4 Potentially avoidable causes of BL/SVI

	Residential schools, N = 227		Integrated schools, N = 221		Total, N = 448	
	N	%	N	%	N	%
<i>Preventable</i>						
Adverse drug reactions	20	8.8	1	0.5	21	4.7
Trauma	6	2.6	5	2.3	11	2.5
Ophthalmia neonatorum	2	0.9	—	—	2	0.4
Subtotal	28	12.3	6	2.7	34	7.6
<i>Treatable</i>						
ROP	50	22.0	28	12.7	78	17.4
Lens disorder	39	17.2	38	17.2	77	17.2
Glaucoma	14	6.2	20	9.0	34	7.6
Uveitis	—	—	3	1.4	3	0.7
Subtotal	103	45.4	89	40.3	192	42.9
Total avoidable	131	57.7	95	43.0	226	50.5

$P = 0.001$.

Table 5 WHO categories of visual loss, using best corrected visual acuity (BCVA), East Malaysia

WHO category	Vision in better eye	Residential schools		Integrated schools		Total	
		N	%	N	%	N	%
No impairment	6/18 or better			1	3	1	2
Visual impairment	<6/18–6/60	1	3	5	17	6	9
Severe visual impairment	<6/60–3/60	4	11	4	14	8	12
Blind	<3/60–NPL	30	86	19	66	49	77
Total		35	100	29	100	64	100

blind schools do not represent the entire population. In this study, our sample of 24 schools caters for only 22.4% of the estimated number of school-age children in Malaysia who are blind. It is likely that children with other physical disabilities may be precluded from attending school. Therefore, children with other disabilities may well be under-represented (eg, children who are cortically blind (often from prematurity), children who are deaf and blind (rubella), and so on). Other reasons why these children may not have got enrolled to these blind schools are because of parental fear, financial difficulty, and social stigma associated with any physical disability. This phenomenon is especially recognized among those from the underdeveloped areas of East Malaysia, and this factor could have reduced the number of children available in our study. Furthermore, none of the schools maintained a registry of the cause of blindness of their students upon enrollment.

Retinal disorders accounted for 33% of the cases, of which ROP was 17.4%, being almost similar to a study from Thailand.¹¹ However, when compared with national study done a decade ago, ROP has increased threefold,⁶ and this is attributed to increasing number of preterm births, survival of very low birth weight infants, and expanding neonatal and maternal services. Malaysia, India, and other developing countries are facing the 'third epidemic', which is a mixture of 'first epidemic' (inadequately monitored oxygen) and 'second epidemic' (extreme prematurity) that reflects varying levels of neonatal care.¹² Screening in a timely fashion is important as there is only a narrow window of opportunity for treating these babies as ROP progresses rapidly.¹³ It has been suggested that IMR could act as a proxy indicator for the risk of blindness in children from ROP, with countries with IMRs in the range 9–60/1000 live births being most at risk.¹⁴ In 2007, the IMR in Malaysia was 62/10 000 (ref. 4) live births, suggesting that blindness from ROP should be largely controlled by very good neonatal care and efficient ROP screening programs that have good coverage.¹⁵ In the developed nations, screening criteria have been formulated for high-risk infants that are reviewed and revised as the population of infants at risk changes with time.¹⁶ In 2005, a national clinical practice guideline (CPG) on ROP was drafted by pediatric ophthalmologists, pediatricians, and the Ministry of Health of Malaysia. Screening should be done at 4–6 weeks after birth, in infants with a birth weight ≤ 1500 g and gestational age ≤ 32 weeks. Infants with an unstable clinical course are screened at the discretion of the attending neonatologist. This criterion is similar to that of the American screening guidelines for ROP.¹⁷ In this study the gestational age was between 25 and 30 weeks. Birth weight (BW) was not obtainable in every case and this was a limitation in our study

as neither the medical records were complete nor the parents had any recollection of the BW.

Being a leading cause of surgically correctable blindness in the developing world, pediatric cataract imposes an enormous problem in terms of morbidity, economic loss, and social burden.¹⁸ Globally the incidence of cataract is 1–15/10 000 live births.² Data on the prevalence of childhood cataract are lacking in Malaysia. In this study, nearly one-third were untreated and of those who received treatment, many were already amblyopic. That the critical period of surgery for unilateral congenital cataract is 6 weeks of age is a well-known fact, and permanent sensory deprivation can occur if surgery is delayed beyond 4 months of age in bilateral dense cataract.¹⁹ In our study, the lens-related disorders accounted for 17.2%, being nearly similar to Thailand (16.9%)¹⁰ and Indonesia (16.4%).²⁰ Fear of surgery, lack of awareness, and knowledge, inappropriate counseling, financial difficulty, large family, and poor parental commitment are all barriers to early detection and successful treatment outcomes. Although the number of cataract cases has reduced over the years from 22.3% (ref. 6) to 17.2%, in this study there is still a pressing need to educate our primary health-care givers and teachers on children's eye health and organize more screening projects at schools to address this issue. Special schools make sure that all students have undergone a thorough ophthalmic examination before enrollment.

Glaucoma/buphthalmos were other causes of treatable visual loss, and the proportion was similar to other studies in the region.^{11,21,22} Pediatric ophthalmic services need to be expanded in Malaysia, and WHO has recommended that there should be one well-equipped child eye-care center for every 10 million population,²³ which would translate to three centers throughout Malaysia. Screening and early detection of glaucoma with appropriate referral to the tertiary care center is required.

Conditions affecting the whole globe were the next commonest cause in Malaysia. Genetic diseases or intrauterine factors could be the probable reasons for this, although in the majority, the cause still remains unknown. Large regional differences exist in the percentages of blind school children with congenital anomalies, ranging from 1.4% in Cuba to 33.2% in Sri Lanka.²¹ Severe visual loss due to congenital abnormalities of the globe is estimated to affect between 0.4 and 16.2/100 000 children in the countries studied.²⁴ More research is needed to determine the contributing factors to these conditions.

Researchers from other Asian countries^{11,15,21–23,25–27} have also reported that the underlying cause of visual loss cannot be determined in a high proportion of

children. In our study, hereditary conditions, mainly retinal dystrophies, were the main identifiable group. Causes of childhood blindness due to tumor, trauma, and drug-induced reactions were relatively uncommon compared with other Asian countries. For example, vitamin A deficiency was not seen in this study population because of the relative affluence of the nation.²⁸ Congenital toxoplasmosis and rubella were the main intrauterine causes. Malaysia adopted the selective vaccination strategy (monovalent vaccine) involving teenage girls 12 years of age in 1987, and in 2002 the universal strategy (MMR vaccine) that immunized all young children in its Expanded Programme of Immunization (EPI). The program has been effective with high coverage rates but the impact is less than desired as cases of congenital rubella syndrome (CRS) are still encountered in the hospitals. There are two reasons to this contradictory statement. First, universal strategy was introduced in 2002 and the direct impact of immunization is not seen yet. Second, herd immunity was expectedly low with the selective strategy of immunization adopted, as younger children who were not the target group remained potential source of infection. The incidence of CRS can be eliminated if high vaccine coverage is maintained throughout.^{29,30} Preventable conditions included ophthalmia neonatorum, drug allergy, and trauma. These findings suggest the importance of primary prevention such as immunization, public health awareness, and education.

Data from other blind school studies show that among genetic eye diseases, retinitis pigmentosa usually predominates (42–80%).³¹ Genetic conditions are becoming relatively more important in Southeast Asian countries that are rapidly developing socioeconomically. Children affected by genetic diseases are often amblyopic and require low vision aid. A study of the profile of low vision involving two special schools in Malaysia reported amblyopia (14%) and childhood nystagmus (15%) as an important cause of visual impairment.³² The majority of these children did not use or own low vision devices because of cost factor and lack of knowledge on how to use the device. Thus, 64 children could have benefited from refraction and unfortunately these are dependent on parental ability to pay. Therefore, once again, awareness, motivation, and education to those in direct contact with the child is of paramount importance.

Children who are able to cope with mainstream learning were enrolled in integrated schools. These children would require specialized teaching strategies to cope with the core curriculum. Our government encourages schools to serve all children regardless of their disabilities.³³

In conclusion, half of the childhood blindness could be avoided, and the pattern of causes reflects upon the socioeconomic status of the country. We need to further improve and implement ROP screening program in the country and this can be achieved by improving awareness about ROP among pediatricians, neonatologists, nurses, midwives, family physicians, public, and, not forgetting, expectant mothers. Counseling parents regarding pediatric cataract should also be an integral part of the service.

Summary

What was known before

- We currently have limited data on the potentially avoidable causes of childhood blindness. We need better understanding of the epidemiology to plan control strategies, as the impact of visual loss extends beyond the child to the family and community, and therefore early recognition and prevention is of prime importance.

What this study adds

- This study is unique as the data were analyzed according to the type of education, whether residential or integrated. The importance of a proper medical assessment before enrollment into a special school requires attention as many children were enrolled without a diagnosis. We need to create awareness among primary health-care workers on how to screen potentially high-risk children to avoid delay in treatment.

Conflict of interest

The authors declare no conflict of interest.

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