WORLD VIEW

Causes and temporal trends of childhood blindness in Indonesia: study at schools for the blind in Java

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Aims: To ascertain the causes of blindness and severe visual impairment (BL/SVI) in schools for the blind in Java, to identify preventable and treatable causes and to evaluate temporal trends in the major causes.

Methods: From a total of 504 students, 479 were examined. Data was collected using a modified World Health Organization Prevention of Blindness (WHO/PBL) eye examination record for children.

Results: The majority of the students (95%) were blind and 4.6% were severely visually impaired. The major anatomical site of BL/SVI was whole globe in 35.9%, retina in 18.9%, lens in 16.4% and cornea in 16.1%. The major underlying aetiology of BL/SVI was undetermined/unknown in 32.7% (mainly microphthalmia, anterior segment dysgenesis and cataract), hereditary factors 31.9% (mainly retinal dystrophies), and childhood disorders 28.5%.

Avoidable causes of BL/SVI accounted for 59.9% of the total students, whereas measles blindness was the underlying condition for 23.1% of the preventable causes; cataract and glaucoma accounted for 15.5% and 8.2% of the treatable causes, respectively. Exploration on trends of SVI/BL among two different age groups <16 years and ≥16 years suggested that childhood disorders and corneal factors have declined, while hereditary disorders have increased. Optic nerve disorder, although not counted as a major cause of blindness, seems to be on the increase.

Conclusions: More than half of the BL/SVI causes are potentially avoidable. Cataract and corneal disorders related to measles or vitamin A deficiency were the major treatable and preventable causes. Declining proportions of childhood factors and corneal disorders over a period of 10–20 years could reflect improved vitamin A supplementation and measles vaccination coverage in Indonesia. This finding, and the increased proportion of hereditary disease causes, could suggest improving levels of socioeconomic development and health care services.

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The prevalence of blindness in children is estimated to range from 0.2–0.3/1000 children in developed countries and 1.0–1.5/1000 children in developing countries, of whom the majority live in Asia.¹

Indonesia is an archipelago consisting of 32 provinces with about 500 ethnic groups. It has a population of 206 264 595 (Central Bureau for Statistics), of which 61 250 199 (26.69%) are children aged under 15 years. It is therefore estimated that approximately 70 million are children aged under 16 years.

Java is the most populated island in the archipelago (fig 1), consisting of six provinces with an estimated population of 121 292 500 (58.80% of the total Indonesian population), approximately 40 million of whom are children aged under 16 years. Extrapolation of these data (1.0/1000 children) comes to an estimated total of approximately 70 000 blind children in Indonesia, of whom 40 000 are from Java alone.

In an attempt to set priorities for control programs of blindness, baseline epidemiological data of the prevalence and major causes of childhood blindness are essential. As registration data of the blind are mostly not available in developing countries, reliable population-based data on the causes of blindness in children are difficult to obtain. No study on causes of childhood blindness in Indonesia had ever been made or reported prior to a recent study at a school for the blind in West Java.² This was an extended study, which enrolled a larger set of samples representing Java, aiming to ascertain the causes of

Abbreviations: ASD, anterior segment dysgenesis; BL, blindness; LCA, Leber's congenital amaurosis; ROP, retinopathy of prematurity; SVI, severe visual impairment; WHO/PBL, World Health Organization Prevention of Blindness

Figure 1 Map of Indonesia and Java.

BL/SVI in school for the blind in Java, to identify preventable and treatable causes, and to explore trends in the major causes.

MATERIALS AND METHODS

Five schools for the blind in Java were visited by the authors (RS, SA) between November 2005 and January 2006.

There are 10 state-owned schools for the blind in Java, with 4 schools having a total number of students ≥ 100 (large school) and 6 schools having a total number of students < 100 (small school).

A total of 504 students from three large schools for the blind (Wiyata-Guna in Bandung in Western Java, Tan-Miyat in Bekasi (a small city near Jakarta) and Budi-Mulyo in Malang in Eastern Java) and two small schools for the blind (Pendowo in Kudus in Central Java and Bhakti-Candrasa in Surakarta in Central Java) were selected randomly for the study using Stratified cluster sampling based on the number of students (large or small school) was used to obtain data from as wide of a geographic area as possible. The schools cater to students who come mainly from the rural areas of Java, but some travel from outside of Java. Information was gathered from interviewing the students, parents (if possible) and school staff, and from reviewing medical records.

A brief history of onset of visual loss, family history, history of consanguinity, ethnic group and place of residence (village/town/city) was taken. The anterior segment was assessed using a slit lamp/hand-held slit lamp or flashlight and loupe. The posterior segment was evaluated by indirect or direct ophthalmoscopy with dilatation of the pupil.

All data were recorded using a modified World Health Organization Prevention of Blindness (WHO/PBL) eye examination record for children, including the anatomical and aetiological classification. Included were all students with an onset of blindness during infant/childhood or before 16 years of age (determined from medical records or information from adults with knowledge of the child's past medical history, or by the presence of nystagmus).

Visual loss was classified according to the WHO categories of BL/SVI.³

Data were entered into a database in Epi-Info, SPSS V.11.5 and Stata-9 statistical software

RESULTS

Of the 504 students enrolled, 25 were excluded for non-compliance and/or absence at the time of examination. A total of 479 students were examined in 5 schools for the blind from 4 of the 6 provinces in Java. Of them, 104 students (21.7%) were from Tan-Miyat School, 165 students (34.4%) were from Wiyata-Guna School, 52 students (10.9%) were from Pendowo School, 57 students (11.9%) were from Bhakti-Chandrasa School and 101 students (21.1%) were from Budi-Mulyo School.

A total of 321 students (67%) were male and 158 (33%) were female. The total number of students with BL/SVI was 477; 95% were blind and 4.6% were severely visually impaired (table 1).

Table 2 Anatomical classification of BL/SVI in 477 students attending schools for the Blind in Java

Anatomical site	Number	%
Whole globe	171	35.9
Phthisical eye	91	19.1
Anophthalmia	8	1.7
Microphthalmia	25	5.2
Buphthalmos	31	6.5
Glaucoma	8	1.7
Post removal of globe/others	8	1.7
Cornea	77	16.1
Staphyloma	19	4.0
Scars	55	11.5
Others	3	0.6
Lens	78	16.4
Cataract	71	14.9
Aphakic/pseudophakic	5	1.0
Others	2	0.4
Uvea	37	7.7
Aniridia	5	1.0
Others (ASD)	32	6.7
Retina	90	18.9
Dystrophy	74	15.5
ROP	5	1.1
Others	11	2.3
Optic nerve	24	5.0
Atrophy	23	4.8
Hipoplusia	1	0.2
Total	477	100.0

ASD, anterior segment dysgenesis; ROP, retinopathy of prematurity.

Anatomical causes of blindness

The anatomical classification of the causes of BL/SVI is shown in table 2. The major anatomical sites of abnormality were the whole globe (35.9%), retina (18.9%), lens (16.4%) and cornea (16.1%). Phthisical eye (19.1%), retinal dystrophies (15.5%), cataract (14.9%) and corneal scars (11.5%) were the most common structural abnormality in the anatomical classification.

Aetiological causes of blindness

The aetiology classification of BL/SVI is presented in table 3.

In 32.7% (156) cases the underlying cause could not be determined. The abnormalities had been present since birth such as microphthalmus, anterior segment dysgenesis (ASD), and cataract (sporadic/non-familial) that could not be definitely classified as being caused by genetic or hereditary factors or events occurring during the intrauterine period.

Hereditary factors were the second most common cause of blindness, identified in 31.9% (152) of the cases, where there was a positive family history of another similarly-affected individual, or well recognised or proven genetic abnormality in the absence of family history according to WHO/PBL eye examination record coding instruction.

Childhood (postnatal) disorders were the third most common cause of blindness, accounting for 28.5% (136) of the cases. Corneal scars, corneal staphyloma and phthisical eye

Table 1 WHO categories of BL/SVI and distribution of visual acuity

WHO category	Visual acuity (better eye)	Number	%
Blind (BL)	NPL	128	26.7
Blind (BL)	$< 3/60$ -PL	327	68.3
Severe visual impairment (SVI)	$< 6/60$ -3/60	22	4.6
Visual impairment (VI)	$< 6/18$ -6/60	2	0.2
No impairment	6/18 or better	0	0.0
Total		479	100

Table 3 Aetiological classification of BL/SVI in 477 students attending schools for the blind in Java

Aetiological factor	Number	%
Hereditary disease	152	31.9
Intrauterine	7	1.5
Perinatal/neonatal (ROP, Conjunctivitis neonatorum)	26	5.4
Postnatal/infancy/childhood	136	28.5
Unknown	156	32.7
Total	477	100.0

ROP, retinopathy of prematurity.

were predominant postnatal factors, mainly attributed to eye infection due to measles and/or vitamin A deficiency.

Avoidable causes of blindness

Overall, 59.9% (286 cases) were potentially avoidable causes of BL/SVI, of which, 33.3% (159 cases) were preventable and 26.6% (127 cases) were treatable (table 4).

In the treatable group, cataract (71 cases) and glaucoma (39 cases) were the most important causes. Of the 71 cataract cases, 51 cases had not had surgery performed, whereas in 31 of the 39 glaucoma cases no treatment had been received prior to the time of examination. Measles blindness accounted for 23.1% of the preventable causes.

Aiming to explore possible trends in the major causes of BL/SVI over time, the data was classified into two age groups, <16 years and ≥16 years (fig 2). In 477 cases, 17.2% (82) were aged <16 years and 82.8% (395) were aged ≥16 years.

Study of the aetiological factors showed that childhood disorders were responsible for 17.1% (14) of cases in those aged <16 years and 31.1% (123) in those aged ≥16 years ($p = 0.010$, χ^2 test for trend). Hereditary disorders were responsible for 41.5% (34) of cases in those aged <16 years and 29.9% (118) in those aged ≥16 years ($p = 0.04$, χ^2 test for trend).

No statistically significant trend was found in the proportion of cases in the two different age groups who were blind from undetermined/unknown factors ($p = 0.867$, χ^2 test for trend).

Study of anatomical aetiology, showed that cases of blindness from lens disorders (cataract) was 14.6% (12) in students aged <16 years and 16.7% (66) in those aged ≥16 years ($p = 0.644$, χ^2 test for trend).

There was no statistically significant trend in the proportion of cases in the different age groups who were blind from retinal and whole globe disorders ($p = 0.636$ and $p = 0.362$ χ^2 test for trend, respectively).

Table 4 Avoidable causes of BL/SVI

Causes	Number	%
Avoidable	286	59.9
Preventable	159	33.3
Measles	110	23.1
Corneal ulcer/infection	25	5.2
Rubella	3	0.6
Toksoplasmosis	2	0.4
Traditional remedy	6	1.3
Teratogenic	2	0.4
Injury	11	2.3
Treatable	127	26.6
Cataract	74	15.5
Glaucoma	39	8.2
ROP	5	1.0
Retinal detachment	8	1.7
Others: ectopia lentis	1	0.2

ROP, retinopathy of prematurity.

The proportion of blindness cases from corneal disorders was 6.1% (5) in students aged <16 years and 18.2% (72) in those aged ≥16 years ($p = 0.006$, χ^2 test for trend).

The proportion of blindness cases from optic nerve disorders was 11.0% (9) in students aged <16 years and 3.8% (15) in those aged ≥16 years ($p = 0.007$, χ^2 test for trend).

DISCUSSION

In order to set priorities in control programs of blindness, baseline epidemiological data of the prevalence and major causes of childhood blindness are essential. Indeed, it is necessary to identify major preventable and treatable causes in each country and to monitor the changing patterns over time.

Given the low estimated prevalence of childhood blindness of 1/1000 children, approximately 40 000 blind or severely visually impaired children will be found in Java, which is almost half of the total number for Indonesia. The present study examined a total of 477 BL/SVI students, with 82 (17.2%) BL/SVI students aged below 16 years. This small number represents a small proportion (less than 1%) of the estimated prevalence of blind children in Java. The majority of the remaining blind children therefore are not covered in the state-owned schools. They might be in an integrated education or in a non-state/private school for the blind, or not in a formal education program due to cultural and/or social reasons. This study must therefore be viewed as coming from a selected group of schools for the blind and having a bias towards older students, mostly coming from non-affluent families and in whom visual loss is to be more severe. These state-owned schools for the blind do not accept students with multiple handicaps, young children aged below 7 years and those who are still very dependent on their parents in their daily life. Priority is given to those with severe visual loss (visual acuity of less than 1 m for finger counting with the better eye), those with restrictions on their daily social activities and those that are educable and trainable.

The present study shows a mixed pattern of causes, with a predominance of unknown aetiologies, hereditary and post-natal/childhood disorders, accounting for 32.7%, 31.9% and 28.5% of cases, respectively.

Congenital ocular anomalies (mainly microphthalmus and ASD) accounted for 32.7% of the BL/SVI cases. The definite aetiology of this anomaly, whether genetically or prenatally acquired (teratogenic agents or intrauterine deformations), is still unknown. The presence of a large proportion of students with visual loss of undetermined aetiology is in accordance with other studies in developing countries such as North India,⁴ Malaysia,⁵ Nigeria⁶ and Sri Lanka,⁷ and could reflect limited scope for investigation and lack of further laboratory exploration of the affected students and family.

Hereditary diseases is the group that is the second most common cause of blindness, of which retinal dystrophies (Leber's congenital amaurosis (LCA) and other type of retinal dystrophies), followed by congenital glaucoma are predominant. Autosomal recessive was the most common mode of

Figure 2 (A) Aetiological factors. (B) Anatomical factors.

inheritance, and has been attributed to the high level of consanguineous marriages in some areas of Java.

Treatable and preventable causes of blindness

More than half (59.9%) of the blindness cases in this study were preventable. Childhood cataract was responsible for 15.5% cases in the treatable group, and one third was familial (hereditary). More than three quarters of the cataract cases should have already received surgery and the remainder had severe visual loss from amblyopia caused by long delay of surgery. Childhood cataract is the leading cause of surgically correctable blindness in most developing countries such as Chile,⁹ Cyprus,¹⁰ India,⁴ the Philippines and Thailand.¹¹

In a separate study we have observed that children with congenital cataracts were often brought in at a late age (over 3 years), with the presence of nystagmus, which can potentially lead to severe amblyopia after surgery. Aphakic glasses followed by proper amblyopic treatment after surgery was often difficult to maintain in rural communities.

Congenital glaucoma was the second most predominant disease in the treatable causes of blindness group. Only 20% of glaucoma cases had received surgical treatment, whereas the remaining untreated cases had resulted in almost total or total blindness.

There are about 17 paediatric ophthalmologists working in Java, with practices mainly in the big cities. Lack of financial resources of the families and their unawareness of the diseases contribute to the delays to treatment. Most students are from

parents in rural communities with a low socioeconomic background. Lack of an eye-screening program in young and pre-verbal children in Indonesia might also contribute to the delay. Early detection followed by early referral and prompt treatment programs for childhood cataract and glaucoma need to be implemented in rural communities in Indonesia in order to achieve better outcomes after surgery.

Corneal scars, corneal staphyloma and phthisical eye were mainly due to measles (110 cases), and were responsible for the highest proportion in the preventable blindness group. The high proportion of measles causing blindness has also been reported in other developing countries such as North India,⁴ Ethiopia¹² and Nigeria.⁶ It has been known that there is a close relationship between malnutrition, vitamin A deficiency and the severity of measles infections.

Changing trends over the period in age groups (fig 2) for corneal disorders and childhood disorders, however, could suggest that this problem has declined over a period of 10 years or more.

This study supports the notion that retinopathy of prematurity (ROP) is not a major problem in childhood blindness in the rural communities of developing countries,¹³ although the incidence tends to increase as the surveillance of premature babies improves. It accounted for only 1.0% of the total cases, which is an underestimation because of the high mortality rates of premature babies in rural centres due the lack of neonatal intensive care units. The low prevalence of ROP in the presenting study is in consistent with studies in China,¹⁴ India⁴ and Sri Lanka.⁷ In Java there are at least five tertiary health centres with neonatal intensive care facilities located in big cities of the provinces to serve their communities. Lack of a referral system for high risk mothers and/or premature or low birth weight babies from health care centres in rural areas to the tertiary specialist centres could contribute to the high mortality rate of premature babies⁸

In urban areas in Indonesia however, where neonatal care units are available, ROP is not uncommon. A high incidence (30.8%) of ROP in premature infants was observed in a separate hospital-based study at Cipto-Mangunkusumo Hospital in Jakarta.¹⁵

Comparison of the causes of BL/SVI in different age of groups needs to be interpreted cautiously because the data are not population based and only a small proportion of blind children receive special education. In addition, the age at which the children become blind from different disorders varies,⁴ so corneal blindness, for example, is a less important cause in younger children than in older children. Hereditary diseases such as retinal dystrophies might not clinically exhibit a profound phenotype until later in adolescence.

The decline in the proportion of corneal diseases and childhood factors causing BL/SVI could reflect improved vitamin A supplementation and measles vaccination coverage in Indonesia. This country has been combating vitamin A deficiency for decades by implementation of vitamin A supplementation targeted to children aged below 5 years through "Posyandu", an integrated primary health care program existing in all over Indonesia. The coverage rate of vitamin A supplementation program has dramatically increased over the years.¹⁶

The increased proportion of hereditary disorders causing BL/SVI over the two different time periods could suggest an improvement of socioeconomic and health care services, though this cannot be proven definitively by this study.

The availability of low-vision aids is very important to optimise the residual vision of the children. Only three of the five schools for the blind were linked to low-vision care service and almost all provided only simple low-vision devices. Improvement in this area is greatly needed to ensure low-vision services with good quality and affordable low-vision devices are provided to schools for the blind in Java.

CONCLUSIONS

In this study more than half of the cases were avoidable (preventable and/or treatable).

The pattern of treatable causes in this study indicates the need for specialist training and services in congenital cataract and congenital glaucoma. It is hereby recommended that community awareness is raised through education, special training is given, provision is made for a oriented-oriented ophthalmologist for cataract surgery and a referral system for expedited care is set up; all this must be developed and implemented to improve the present poor conditions.

This study suggests changing trends in corneal blindness and childhood factor related blindness in Indonesia. Nevertheless, ensuring high coverage rates of measles vaccination and vitamin A supplementation for the short and long term needs to be rigorously pursued.

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