

Inonesia Severe visual impairment

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The epidemiology of childhood blindness and severe visual impairment in Indonesia

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ABSTRACT

Background The magnitude of blindness among children in Indonesia is unknown. In this study, we aimed to define the magnitude and aetiology of childhood blindness in two parts of Indonesia.

Method Children aged 0–15 years, identified through key informant method and from special schools and community-based rehabilitation programme in Sumba and Yogyakarta, were assessed following WHO protocol and definitions for ophthalmological assessment and classification of visual impairment and blindness among children.

Results Out of 195 children assessed, 113 had blindness/severe visual impairment (BL/SVI), 48 had visual impairment (VI) and 34 no VI. 43.4% children with BL/SVI were female. The main anatomical site of BL/SVI was lens (n=35, 31.0%), followed by retina (n=13, 11.5%) and cornea (n=9, 8.0%). Among the known aetiologies, childhood factors predominated (n=14, 12.4%), followed by hereditary diseases (n=12, 10.6%) where parental consanguinity was found among 33.3% (n=4) of them. Overall, 77.8% (n=88) had avoidable causes of BL/SVI: 69.0% (n=78) treatable (8.8% (n=10) preventable causes. The estimated prevalence of BL/SVI was 0.25 (95% CI 0.19 to 0.32) and 0.23 (95% CI 0.18 to 0.29) per 1000 children in Sumba and Yogyakarta, respectively. The estimated prevalence of cataract was 0.07 per 1000 children (95% CI 0.04 to 0.12) in Sumba and 0.05 per 1000 children (95% CI 0.03 to 0.09) in Yogyakarta. Based on our conservative estimates, there are 17 241 children with BL/SVI in Indonesia; 4270 are blind due to cataract.

Conclusion The magnitude of childhood BL/SVI in Sumba and Yogyakarta is high. Our study suggests that a large proportion of childhood BL/SVI in Indonesia is avoidable.

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INTRODUCTION

Childhood blindness is a major public health issue with an estimated 1.4 million blind children globally.¹ Reliable data on blinding eye diseases among children are difficult to obtain due to methodological challenges; large sample sizes are required for precise estimation of the prevalence and reliable investigation into aetiology. The estimated prevalence of childhood blindness ranges from 3 to 15 per 1000 children globally and 9 per 10 000 children in low and middle-income countries (LMIC).¹

The VISION 2020 is a joint initiative of The WHO and The International Agency for the Prevention of

Blindness which identified childhood blindness as a priority for control.² It was also estimated that at least 45% of childhood blindness globally are due to avoidable causes.³ Evidence suggests that there is substantial variation in the prevalence and aetiology of blindness across the socioeconomic spectrum.⁴ Low prevalence within defined areas often limit epidemiological studies for exploration of prevalence and causes of childhood blindness.⁵ Moreover, lack of specific training, expertise and equipment in LMICs restrict exploration of childhood blindness.⁶

Indonesia is the fourth most populous country in the world with an estimated population of 260 580 739 in 2017, of which more than a quarter is child population (aged under 15 years).^{7,8} It ranks 113th out of 188 countries in Human Development Index.⁹ However, there is no population-based data on the prevalence and causes of childhood blindness in Indonesia although studies found that the prevalence of blindness is substantially high among adult population.^{10 11}

Conventional surveys of childhood blindness could generate precise estimates of burden data; however, they are time-consuming and expensive. Key informants method (KIM) is a novel effective method of case ascertainment at community level, tested in many LMICs that involves training of local volunteers familiar with the community and the local context to act as key informants (KIs) for identifying disabled children in the community to facilitate case identification and recruitment of study participants.^{5 6 12–16} KIM can potentially aid in overcoming the obstacles of epidemiological studies on childhood blindness in LMICs like Indonesia. We aimed to define the prevalence of childhood blindness and severe visual impairment (BL/SVI) in selected parts of Indonesia using KIM.

We selected two distinct locations, Sumba and Bantul district of Yogyakarta) for this study to explore the epidemiology of childhood blindness in an urban district and a rural remote island in Indonesia.

Sumba is a small, impoverished remote rural island in Indonesia with projected population of 746 628 (child population 206 465). It has no eye care services; there is no eye hospital or ophthalmologist in Sumba. The population of this island is met with several challenges including widespread poverty, poor education and lack of health facilities. In contrast, Yogyakarta is an urban city with relatively developed health system run by the



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government complemented by non-governmental organisation support where tertiary level eye care services are available at Universitas Gadjah Mada (UGM), a public university located in Yogyakarta, and Hasanuddin University in Makassar. Bantul district of Yogyakarta has a projected population of 991 898 (child population 274 289) in 2017.

METHODS

Recruitment of BL/SVI children

Participants' recruitment took place between January 2015 and June 2016. Children aged 0–15 years were assessed to explore the epidemiology of childhood blindness in two areas of Indonesia (ie, Sumba and Yogyakarta) following a WHO developed protocol for studying childhood blindness.¹⁷

The following sources were used:

Key informants

Twelve trained community mobilisers (six in each of the two study sites) identified KIs in the study area who then received structured training on identification of children with BL/SVI. During the study period, 1282 KIs (574 in Sumba and 708 in Yogyakarta) were trained. The KIs identified children/families and informed them of the ophthalmological assessment camps.

Schools for special education

Participants were recruited from children attending schools for special education (SpEdu) in Sumba and Yogyakarta.

Community-based rehabilitation programmes

Study participants were recruited from active community-based rehabilitation (CBR) programmes for children with SVI/BL in Sumba.

Inclusion criteria

Children aged 0–15 years were eligible for inclusion. The WHO categories of visual impairment were used which defines blindness (B) as presenting visual acuity (ie, with glasses if normally worn) of less than 3/60 and severe visual impairment (SVI) as presenting visual acuity of 3/60 to less than 6/60 in the better eye.¹ Visual impairment (VI) was defined as visual acuity of 6/60 to 6/18. Children with unilateral blindness were excluded.

Data collection

Study participants were examined using the WHO protocol for examination and recording of eye data for children with blindness and low vision.¹ Standard WHO data collection form for childhood blindness was used. The details of the method of data collection, ophthalmological assessment and data analysis have been outlined in a previous study implemented by the study team using the same protocol.⁶ The medical team included five ophthalmologists and two paediatric ophthalmologists assisted by two resident physicians sourced from University of Hasanuddin, Makassar and UGM, Yogyakarta. The principal investigator (MM) provided protocol specific training to the team of ophthalmologists on the data collection tool. Examinations were performed by ophthalmologists in hospital compounds or suitable locations close to the children's residence. Sociodemographic information, relevant ophthalmic, medical and family histories were also collected.

Ophthalmological assessment

Presenting distance visual acuity (ie, with optical correction if usually worn) were assessed in each eye separately and then in

both eyes together using a reduced logarithm of minimum angle of resolution E chart, at 6 or 3 m. Cardiff acuity cards were used for preschool children, employing the standard staircase method. Near vision was tested with an E chart with N5–30 font sizes with both eyes open. Visual fields were assessed by confrontation when indicated. Anterior segment examination was carried out using a magnifying loupe and torch. Posterior segments were dilated for examination by direct and indirect ophthalmoscopy. Intraocular pressure was not measured. All children were assessed for refractive error. Cycloplegic refraction was performed unless it was considered clinically inappropriate (eg, dense cataract), using retinoscopy and trial lenses. Assessment of refractive error was made with a multiple pinhole, or with corrective lenses after refraction. Diagnosis of refractive error was made if the acuity improved to normal, that is 6/18 or better, with refraction. Those requiring surgical, medical or optical treatment were referred to the collaborating eye hospitals.

Classification of causes

The WHO classification system was followed to categorise anatomical site and underlying aetiology of BL/SVI.¹³ Preventable, treatable and unavoidable causes of BL/SVI were established based on history, clinical and ophthalmological assessment.

Anatomical site of abnormality

All structural abnormalities for each eye were recorded. Detailed definitions and criteria in the WHO coding instructions were used to select one site for each eye. For instance, cataract is defined as central lens opacity sufficient to reduce visual acuity. As per WHO guidelines, one site, either that in the right or left eye of the child, was selected to represent the major site. Prioritisation was given for treatable causes and then for the preventable causes if the main sites differed between eyes.

Underlying aetiology

Efforts were made to determine the time of onset of the insult leading to visual loss based on family history, ocular history, clinical findings and diagnosis. Hereditary, intrauterine, perinatal and childhood factors were used as the categories according to WHO guidelines.

Preventable, treatable and unavoidable causes

Preventable causes constitute conditions that could have possibly been avoided through simple interventions in households or in the community such as health promotion, prevention and education. Treatable causes consist of conditions where sight could have been restored or preserved through surgical, medical or optical interventions (eg, glaucoma or cataract surgery). Avoidable blindness includes all the treatable and preventable causes, while the rest were considered to be unavoidable. Preventable, treatable and unavoidable categories were mutually exclusive for diagnosis and subsequent analysis.

Ethical approval

The purpose of the study and the examination procedure were explained to subjects, and informed written consent was obtained from the parents or primary caregivers of the study participants. The consent form included their signature or fingerprint along with their name, address and the date, time and place where the consent was undertaken.

Statistical analysis

Analysis of demographic and clinical variations between study sites has been conducted. X^2 test was performed to determine associations. Prevalence of BL/SVI was calculated with 95% CI using the following formula: total number of children with BL/SVI divided by the total child population in the study area \times 1000. Prevalence of cataract was also calculated similarly. Projected child population in Sumba and Yogyakarta in 2017 was calculated for this purpose using the population growth rate in Indonesia and the 2010 national census data.^{18,19} The level of significance was set at p value < 0.05 .¹⁸ Statistical analyses were conducted using Statistical Package for the Social Sciences (IBM SPSS Statistics V.23, Somers, New York, USA).²⁵

Extrapolation of the study prevalence data was used to estimate the total number of children with BL/SVI and cataract in Indonesia. The estimated population of Indonesia in 2017 was used to estimate the total number of children in Indonesia (27.7% of total population) and the proportion of the population living in urban (53.7%) and rural (46.3%) settings.^{7,8,20} Extrapolation of our observed prevalence was used to estimate the total number of children with BL/SVI and cataract in Indonesia.

RESULTS

A total of 195 children were assessed (103 were from Sumba and 92 from Yogyakarta) of which 113 had BL/SVI, 48 with VI and 34 had no VI. Among the children with BL/SVI ($n=113$), 51 (45.1%) were from Sumba and 62 (54.9%) were from Yogyakarta. 43.4% children with BL/SVI were female.

Of the 113 children with BL/SVI, nearly a third ($n=72$, 63.7%: 41 from Sumba and 31 from Yogyakarta) were recruited through KIM followed by 29.2% from SpEdu ($n=33$: 2 from Sumba and 31 from Yogyakarta). 7.1% ($n=8$) children were recruited from CBR programmes all of which were from Sumba.

Demographic details of study participants

The mean age of the children with BL/SVI was 9.6 years ($SD \pm 4.1$ years). The major demographic characteristics of children with BL/SVI have been shown in table 1.

Prevalence of BL/SVI

The estimated prevalence of BL/SVI was 0.25 per 1000 children (95% CI 0.19 to 0.32) in Sumba and 0.23 per 1000 children (95% CI 0.18 to 0.29) in Yogyakarta. The estimated prevalence of cataract was 0.07 per 1000 children (95% CI 0.04 to 0.12) in Sumba and 0.05 per 1000 children (95% CI 0.03 to 0.09) in Yogyakarta.

Extrapolating the study prevalence to the projected child population in Indonesia in 2017, it is estimated that there are 17 241 with children with BL/SVI in Indonesia of which 4270 are blind due to cataract.

Anatomical site of abnormalities for children with BL/SVI

The main anatomical site of BL/SVI was lens abnormalities ($n=35$, 31.0%) followed by retinal conditions ($n=13$, 11.5%) and corneal disorders (9 out of 113, 8.0%) (table 2).

The main site of abnormality was lens for both Sumba (33.3%) and Yogyakarta (29.0%) followed by retina (13.7 in Sumba vs 9.7% in Yogyakarta) and cornea (13.7% in Sumba vs 3.2% in Yogyakarta). Globe appeared normal in almost half (46.8%) of the children with BL/SVI from Yogyakarta compared with only one quarter (23.5%) in Sumba ($P=0.02$) as 45.2% of children in Yogyakarta had refractive error compared with 7.8% in Sumba (table 2).

Lesions of the whole globe were most common among children below 5 years of age (3 out of 17, 17.6%), followed by abnormalities of lens (2 out of 17, 11.8%) and cornea (2 out of 17, 11.8%). On the other hand, lens abnormality was the most common cause of BL/SVI among children aged 5 to < 10 years ($n=12$, 41.4%) and ≥ 10 years ($n=21$, 31.3%) followed by retinal lesions (approximately 13% for both age groups) (table 2).

Underlying aetiology of BL/SVI

In over two-thirds of the cases, an underlying aetiology could not be determined ($n=79$, 69.9%). Among the known aetiologies, childhood factors predominated ($n=14$, 12.4%), followed by hereditary diseases ($n=12$, 10.6%). Among children with a

Table 1 Demographic characteristics of children with blindness/severe visual impairment

Demographic characteristics	Sumba			Yogyakarta		Total
	CBR	KI	SpEdu	KI	SpEdu	
Age group (years)	< 5	2 (25.0)	14 (34.1)	0 (0.0)	1 (3.2)	17 (15.0)
	5 to < 10	0 (0.0)	14 (34.1)	1 (50.0)	7 (22.6)	29 (25.7)
	≥ 10	6 (75.0)	13 (31.7)	1 (50.0)	23 (74.2)	67 (59.3)
Sex	Female	6 (75.0)	15 (36.6)	0 (0.0)	16 (51.6)	49 (43.4)
	Male	2 (25.0)	26 (63.4)	2 (100.0)	15 (48.4)	64 (56.6)
Family history	Yes	0 (0.0)	8 (19.5)	0 (0.0)	10 (32.3)	22 (19.5)
	No	7 (87.5)	32 (78.0)	2 (100.0)	20 (64.5)	88 (77.9)
	Unknown	1 (12.5)	1 (2.4)	0 (0.0)	1 (3.2)	3 (2.7)
History of consanguinity	Yes	1 (12.5)	11 (26.8)	0 (0.0)	0 (0.0)	13 (11.5)
	No	5 (62.5)	27 (65.9)	2 (100.0)	30 (96.8)	93 (82.3)
	Unknown	2 (25.0)	3 (7.3)	0 (0.0)	1 (3.2)	7 (6.2)
Time of onset	Congenital	3 (37.5)	15 (36.6)	1 (50.0)	13 (41.9)	52 (46.0)
	Infantile	1 (12.5)	8 (19.5)	1 (50.0)	3 (9.7)	17 (15.0)
	1 to < 5 years	0 (0.0)	10 (24.4)	0 (0.0)	4 (12.9)	15 (13.3)
	≥ 5 years	0 (0.0)	4 (9.8)	0 (0.0)	11 (35.5)	20 (17.7)
	Unknown	4 (50.0)	4 (9.8)	0 (0.0)	0 (0.0)	9 (8.0)
Total	8 (100.0)	41 (100.0)	2 (100.0)	31 (100.0)	31 (100.0)	113 (100.0)

CBR, community-based rehabilitation; KI, key informant; SpEdu, schools for special education.

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Table 2 Main anatomical site of abnormality among children with blindness/severe visual impairment by study site and age

Anatomical site	Total, n (%)	Site		P value	Age (years)		
		Sumba, n (%)	Yogyakarta, n (%)		< 5 n (%)	5 to < 10 n (%)	≥ 10 n (%)
Globe appears normal	41 (36.3)	12 (23.5)	29 (46.8)	0.02	8 (47.1)	9 (31.0)	24 (35.8)
Lens	35 (31.0)	17 (33.3)	18 (29.0)	NS	2 (11.8)	12 (41.4)	21 (31.3)
Retina	13 (11.5)	7 (13.7)	6 (9.7)	NS	0 (0.0)	4 (13.8)	9 (13.4)
Cornea	9 (8.0)	7 (13.7)	2 (3.2)	NS	2 (11.8)	1 (3.4)	6 (9.0)
Whole globe	8 (7.1)	3 (5.9)	5 (8.1)	NS	3 (17.6)	1 (3.4)	4 (6.0)
Optic nerve	4 (3.5)	3 (5.9)	1 (1.6)	NS	0 (0.0)	2 (6.9)	2 (3.0)
Uvea	2 (1.8)	1 (2.0)	1 (1.6)	NS	1 (5.9)	0 (0.0)	1 (1.5)
Glaucoma	1 (0.9)	1 (2.0)	0 (0)	NS	1 (5.9)	0 (0.0)	0 (0.0)
Total	113 (100.0)	51 (100.0)	62 (100.0)		17 (100.0)	29 (100.0)	67 (100.0)

hereditary aetiology (n=12), history of parental consanguinity was found in 33.3% (n=4) cases. Intrauterine (6 out of 113, 5.3%) and perinatal (2 out of 113, 1.8%) causes such as congenital rubella syndrome and toxoplasmosis, and perinatal factors including retinopathy of prematurity (ROP) were less common (table 3).

Preventable, treatable and unavoidable causes of BL/SVI

Overall, 88 children (77.8%) had avoidable causes of BL/SVI: 69.0% (n=78) of the children had treatable causes and 8.8% (n=10) had preventable conditions (table 4). Preventable causes were more commonly observed in Sumba, whereas treatable causes were more common in Yogyakarta (P=0.001) (table 4).

Preventable causes were equally prevalent for both genders (50.0% for both). However, boys were more likely to have treatable causes (55.1% vs 44.9%) and unavoidable causes (64.0% vs 36.0%).

Preventable causes were more common in Sumba than in Yogyakarta (13.7% vs 4.8%), whereas treatable causes were more common in Yogyakarta (80.6% in Yogyakarta vs 54.9% in Sumba). Nearly two-thirds (38 out of 10, 60%) of the preventable causes were attributed to vitamin A deficiency. Out of the five children with vitamin A deficiency in Sumba, three of them were in the age category of 10 years and above (11, 11 and 13 years) and the two other children were aged 4 years and 5 years. Other preventable causes included infections (3 of 10, 30.0%) and trauma (1 out of 10, 10.0%).

41.0% (n=32) and 37.2% (n=29) of the treatable causes were due to refractive error and cataract, respectively. A total of 25 children (22.1%) had unavoidable causes of BL/SVI, including congenital eye anomaly (7 out of 25, 28.0%), retinal dystrophies (7 out of 25, 28.0%) and optic nerve disease (4 out of 25, 16.0%). No significant age differences were observed between children with and without avoidable causes.

Table 3 Underlying aetiology of blindness/severe visual impairment

Aetiology	Total	Sumba	Yogyakarta
	n (%)	n (%)	n (%)
Unknown aetiology	79 (69.9)	32 (62.7)	47 (75.8)
Postnatal/childhood factor	14 (12.4)	10 (19.6)	4 (6.5)
Hereditary disease	12 (10.6)	7 (13.7)	5 (8.1)
Intrauterine factor	6 (5.3)	2 (3.9)	4 (6.5)
Perinatal/neonatal factor	2 (1.8)	0 (0)	2 (3.2)
Total	113 (100.0)	51 (100.0)	62 (100.0)

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Causes in relation to the age at onset of visual loss

Nearly half of the children (n=52, 46.0%) reported being blind since birth, and 75.2% (n=85) were BL/SVI before their fifth birthday. 48.6% (n=17) of the lens-related BL/SVI were congenital and an additional 17.1% (6 out of 35) occurred before the age of one year. On the other hand, two-thirds (6 out of 9, 66.7%) of corneal conditions occurred after birth. 80.0% (8 out of 10) of preventable causes and 73.1% (n=57) of treatable conditions led to BL/SVI before the age of 5 years.

DISCUSSION

To the best of our knowledge, this is one of the first population-based epidemiological study on BL/SVI among children in Indonesia. The estimated prevalence from our study suggests a high magnitude of BL/SVI in Indonesia, and a large proportion of it is due to avoidable causes (ie, preventable and treatable).

In our study, 77.8% children had avoidable causes of BL/SVI. Another study from Java, Indonesia, found that 59.9% of childhood BL/SVI were avoidable; however, that study only included participants from schools for blind children.²¹ Lens abnormality, primarily unoperated cataract, was the most common cause of BL/SVI in our study and a large majority of these cases occurred under the age of one year.

Results from our study are comparable to findings from a population-based study in India where 66.7% children had avoidable causes of BL/SVI.²² The lens was identified to be the primary site of abnormality (mainly unoperated cataract) in KIM studies conducted in other LMICs including Malawi (35.0%),⁴⁸ Tanzania (27.0%) and Bangladesh (42.3%).^{6, 23, 24} However, our findings differ from other studies in LMICs where cases were ascertained from schools for blind children or hospitals. According to those studies, lens accounted for 10%–20% of all cases of BL/SVI.²⁵ One explanation is that those studies have recruited children from SpEdu, where the children, on being identified with cataract, underwent surgical correction and discontinued attending the special schools after restoration of their sight and probably moved to regular school.

In addition, special school-based studies probably underestimate cataract-related blindness because children with cataract living in rural remote communities are less likely to attend special schools and tertiary eye care centres with paediatric ophthalmology units. Usually these facilities are located in major cities. So, KIM provides a more accurate reflection of the situation of blindness in the population compared to institution-based studies.

The prevalence of xerophthalmia and corneal disease in Indonesia declined by 95% and 75% respectively between 1977–1978

Table 4 Preventable, treatable and unavoidable causes of BL/SVI

Causes of BL/SVI		Sumba	Yogyakarta	Total
		n (%)	n (%)	n (%)
Preventable	Vitamin A deficiency	5 (9.8)	1 (1.6)	6 (5.3)
	Trauma	1 (2.0)	0 (0)	1 (0.9)
	Chorioretinitis	0 (0.0)	1 (1.6)	1 (0.9)
	Ocular toxoplasmosis	1 (2.0)	0 (0.0)	1 (0.9)
	Phthisical eye post orbital cellulitis	0 (0.0)	1 (1.6)	1 (0.9)
	Subtotal	7 (13.7)	3 (4.8)	10 (8.8)
Treatable	Refractive error	4 (7.8)	28 (45.2)	32 (28.3)
	Cataract	15 (29.4)	14 (22.6)	29 (25.7)
	Aphakia/pseudophakia	2 (3.9)	3 (4.8)	5 (4.4)
	Glaucoma	3 (5.9)	0 (0)	3 (2.7)
	Keratoconus/dystrophy	1 (2.0)	1 (1.6)	2 (1.8)
	Retinal detachment	0 (0)	1 (1.6)	1 (0.9)
	Uveitis	1 (2.0)	0 (0)	1 (0.9)
	Retinopathy of prematurity	0 (0.0)	3 (4.8)	3 (2.7)
	Squint	1 (2.0)	0 (0.0)	1 (0.9)
	Amblyopia	1 (2.0)	0 (0.0)	1 (0.9)
	Subtotal	28 (54.9)	50 (80.6)	78 (69.0)
	Unavoidable	Congenital eye anomaly	2 (3.9)	5 (8.1)
Retinal dystrophies		5 (9.8)	2 (3.2)	7 (6.2)
Optic nerve disease		3 (5.9)	1 (1.6)	4 (3.5)
Cortical blindness		0 (0.0)	1 (1.6)	1 (0.9)
Cortical visual impairment		5 (9.8)	0 (0.0)	5 (4.4)
Microphthalmos		1 (2.0)	0 (0.0)	1 (0.9)
Subtotal		16 (31.4)	9 (14.5)	25 (22.1)
Total	51 (100.0)	62 (100.0)	113 (100.0)	

BL, blindness; SVI, severe visual impairment.

and 1992.²⁶ In our study, only six children had BL/SVI due to vitamin A deficiency. Efforts towards prevention of nutritional deficiencies, effective child survival programme and increased immunisation coverage have resulted in reduced morbidity and increased survival.²⁷ These global initiatives resulted in reduction of BL/SVI due to vitamin A deficiency which is reflected in our study findings. Although vitamin A deficiency-related blindness has been reduced markedly, other avoidable causes ie, refractive error (28.3%) and cataract (25.7%), continue to prevail as the leading causes of BL/SVI among our study population. These can be treated through simple interventions such as spectacle correction of refractive errors and increased surgical coverage for cataract. In our study, 36.3% were found to have normal globe (mostly refractive error) during ophthalmic examination, followed by 31.0% with lens-related pathology (mainly unoperated childhood cataract). Among those who had normal globe (n=41), 32 (78.0%) had uncorrected refractive error.

Substantially higher proportion of children (45.2%) in Yogyakarta had refractive error compared with Sumba (7.8%). A similar pattern was observed in a study comparing the magnitude of uncorrected refractive error among children in urban and rural areas in India, which showed that the prevalence of uncorrected refractive error was significantly higher among children of urban area compared with children of rural area.²⁸

ROP was not a major cause of BL/SVI in our study population in Indonesia, and all three cases of ROP were diagnosed in Yogyakarta, a relatively developed urban area. It is highly likely that premature babies may not be surviving to develop ROP. Neonatal mortality is high in Indonesia (neonatal fatality rate: 19 deaths per 1000 live births),⁷ and there is a lack of access

to neonatal intensive care and special care services for most communities in Indonesia. With the development of neonatal care support in Indonesia, particularly in the urban areas, the burden of ROP is likely to be greater with increased survival of preterm babies.

In our study, the significant difference observed in underlying aetiology in urban (Yogyakarta) and rural (Sumba) settings is also notable. The children in rural areas are more commonly affected by preventable and unavoidable causes, whereas the children in urban Yogyakarta are primarily affected by treatable causes of BL/SVI. There is marked differences in the availability of services and sociodemographic characteristics in the two study sites. It is likely that these factors collectively contributed to the differences in the aetiology of BL/SVI observed in the two areas and consequently the age of the children affected by them in Sumba and Yogyakarta. There is also notable difference in the age distribution of children with BL/SVI in the two locations. This may have resulted from the difference in the proportion of children recruited by each method in Sumba and Yogyakarta as the mean age of the children recruited by the different methods varied (KIM: 8.8 years, SpEdu: 11.1 years and CBR: 6.6 years).

Based on the observed prevalence, there is an estimated 17 241 children with BL/SVI in Indonesia. There is a substantial unmet need for services for children with special needs in Indonesia where only 4% of children with disability have access to special education.²⁹

The distribution of eye health workers presents a challenge for policy and access in Indonesia as most of the eye care services are concentrated in major cities/urban area. Lack of an eye screening programme for early diagnosis and interventions for blinding

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eye diseases among children in Indonesia might have contributed to this substantial burden of avoidable blindness. Screening should focus on red reflex testing soon after birth for detection of cataract and other interventions need to be integrated into the primary level of healthcare delivery. Early detection followed by early referral and prompt treatment supported by comprehensive eye care services for childhood cataract and refraction services for children and other treatable and preventable causes of blindness need to be implemented in Indonesia.

This study used the KIM to identify children with BL/SVI from the communities. KIM has been successfully implemented in other LMICs and case ascertainment (ie, BL/SVI) is reasonably high in KIM compared with other conventional survey methods.^{6 15} It has been shown to be a suitable alternative to large-scale surveys in LMICs due to its advantages, previous successes in low-resource settings and cost-effective nature.^{6 12 16 23 30}

Study limitations

Indonesia is a large island country with heterogeneous population. This small but unique study was conducted in only two areas of Indonesia. Hence, our study findings are not representative of Indonesia. However, they provide a glimpse into the epidemiology of children with BL/SVI in a remote island and a comparably developed city. We have recruited study participants through KIM and from SpEdu centres. It is possible that some children may have been missed who were not attending special schools and were not identified by KIM. There is potential underascertainment of young children in Yogyakarta where majority of children were aged 10 years or above. This reflects the potential bias inherent to recruitment of children mainly from SpEdu in Yogyakarta and the challenges of using KIM in an urban area. Moreover, neonatal services have only become established in Yogyakarta over the past decade. Hence, children blind from ROP would have been too young for SpEdu centres and might have been missed by the KIs. However, studies in Bangladesh on childhood disabilities including SVI showed good agreement in the prevalence results between KIM and door-to-door-survey for SVI.³¹ Nevertheless, this study provides useful baseline data which are important for informing service delivery. Additionally, childhood BL/SVI is not a common condition. Consequently, the sample size in our study was relatively small which limited advanced statistical analyses. Another limitation was that we found a large number of cases of BL/SVI with normal globe, but this may be due to refractive error (eg, high myopia) among those children. Moreover, a high negative dioptre lens can improve the vision of individuals who are blind due to moderate-to-severe nuclear cataract to an extent. This leads to misclassification of these cases as blindness due to refractive error, resulting in an overestimate of refractive error blindness, as cataract-related index myopia is attributed to refractive error.³²

Conclusion

The magnitude of childhood blindness and visual impairment in Sumba and Yogyakarta is high. Although causes are largely unknown, the findings suggest that a large proportion is due to avoidable causes. Ensuring inclusive and comprehensive eye care services and improving the access to cataract surgical and refraction services for children would be the most important steps towards the elimination of avoidable childhood blindness in Indonesia.

Contributors MM was responsible for study conception, securing funding, study implementation, data analysis and manuscript development. He is also the data custodian. GK contributed in study design, data analysis and development of the manuscript. TK was responsible for data entry, data analysis, study report writing

and preparation of the first draft of the manuscript. JJ, DH, HSM, S and DW contributed in study implementation and manuscript development. All authors approved the final version to be published.

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Competing interests None declared.

Patient consent Written consent obtained.

Ethics approval Ethical approval was obtained from the review committee of the Asian Institute of Disability and Development (AIDD HREC ref no: southasia-irb-2014-8-01), Bangladesh, Hasanuddin University, Sumba (HREC ref no: UH15100639) and Universitas Gadjah Mada (UGM), Yogyakarta, Indonesia (Ref no: FK/600/EC/2016).

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The epidemiology of childhood blindness and severe visual impairment in Indonesia

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