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Prevalence of ROP in Indonesia: results from School for the Blind studies in Java Island

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Purpose: To estimate the prevalence of retinopathy of prematurity (ROP), an avoidable cause of childhood blindness, in Schools for the Blind students representative of rural areas of communities of Java Island, Indonesia.

Methods: Four-hundred and seventy-nine of a total of 500 students from five Schools for the Blind in Java Island, Indonesia, were examined using the standard WHO / PBL eye examination record for blindness and low vision protocol. Data were analyzed for those aged less than 16 years or the onset of visual loss less than 16 years. Data on social demography and medical history factors were collected. ROP was defined when cicatrical retinal detachment or retinal tractional dates from infancy, or a history of prematurity or low birth weight and ocular findings consistent with this diagnosis were identified.

Results: Most of the students (95%) were blind (BL); 4.6% had severe visual impairment (SVI) and 0.4% visual impairment (VI).

ROP was identified in only 5 of 479 (1.1%) cases. This low prevalence is in accordance with other School for the Blind studies in India (0.5%) and China (1.9%), but is in contrast to those in industrialized countries such as UK (18%) and USA (8–19%).

Conclusions: The low incidence of ROP found in our study is most likely the result of the high mortality rate of premature children in the rural areas of Indonesia like in other developing countries. This finding highlights the need for a better interaction between primary and secondary health care and the specialist tertiary centers (and their intensive neonatal care services), to provide high coverage referral access for high risk mothers and / or premature or low-birth weight infants. This may help to, first, increase the survival rate of this group of babies, and then, as a next step, to install adequate screening programs by pediatric ophthalmologists and retina specialists to diagnose and treat ROP in due time.

Key words: retinopathy of prematurity (ROP), School for the Blind, Indonesia, rural area

INTRODUCTION

Retinopathy of prematurity is characterized by abnormal vascular development of retina in premature infants. In its more severe forms, it results in severe visual impairment or blindness, both of which carry a high financial cost for the community but also a high individual cost by affecting the normal motor, language, conceptual, and social development of the child, which are amplified when the child commences formal education.

The Global Initiative of Avoidable Blindness (1) targets ROP for prevention and treatment in an effort to reduce the prevalence of childhood blindness. In addition, the World Health Organization's: Vision 2020 Program has identified ROP as an important cause of blindness in both high and middle income countries. In the United Sates, ROP remains the second most common cause of childhood blindness.

The prevalence of blindness in children is estimated to range from 0.2 to 0.3 per 1000 children in developed countries and 1.0 to 1.5 per 1000 children in developing countries (Foster A, Gilbert C. Epidemiology of childhood blindness. Eye 1992; 6: 173–6).

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Indonesia has a population of 206,264,595 (Central Bureau for Statistics, 2000), of which 61,250,199 (26.69%) are younger than 15 years. Java Island consists of six provinces with estimated population of 121,292,500 (or 58.80% of the total Indonesian population), of which 34,265,400 are younger than 15 years. Extrapolation of these data estimates a figure of approximately 60,000 to 90,000 blind children in Indonesia, or 34,000 to 51,000 in Java.

MATERIALS AND METHODS

Five schools for the blind in three of six provinces in Java Island, Indonesia were selected by stratified random sampling for the study based on the number of blind children in the school, and to obtain as wide a geographic distribution as possible. All of the school were located not in the capital cities of provinces.

Five-hundred seventy nine of the total 500 students were examined using the standard WHO / PBL eye examination record for blindness and low vision protocol. Twenty three students were excluded from the study, because they were not present at the visiting time to the school for the blind.

Blindness was defined according to WHO as visual acuity of <3 / 60 or less, while severe visual impairment (SVI) as visual acuity between 3 / 60 to <6 / 60.

Data were analyzed for those aged less than 16 years or the onset of visual loss less than 16 years. Data on social demography and medical characteristics were collected. ROP was defined as a mark when cicatrical retinal detachment or retinal tractional dated from infancy, or a history of prematurity or low birth weight and ocular findings consistent with this diagnosis were identified.

RESULTS

Four-hundred and ninety-seven students were enrolled in the study, their mean age was 21.5 years (range, 7–40 year). There were 321 (67%) male and 158 (33%) female students. Most of the students (95%) were categorized as blind, whereas 4.6% as having severe visual impairment (SVI)

Of the total 479 cases, there was only 5 (1.1%) cases of blindness due to ROP, all of them presenting an advanced stage of ROP at the time of examination, with visual acuity ranging from hand movement to light perception.

Table. **Frequency of blindness attributable to ROP reported in different countries**

	Total	**ROP** n (%)	**References**
High income countries			
US	ND	8–19%	Munoz B.[2]
UK	107	19 (18%)	Alagaratnam J[3]
Upper middle income countries			
Czech	229	96 (41.9%)	Kocur I[4]
Lower middle income countries			
China	1245	1.9–2%	Hornby SJ[5]
Indonesia	497	5 (1.1%)	Present study
Sri Lanka	255	0 (0.0%)	Eckstein MB[6]
Low income countries			
India	703	3 (0.5%)	Titiyal JS[7]
Ethiopia	360	ND	Kello AB[8]
Nigeria	142	0 (0%)	Ezeqwui IR[9]

DISCUSSION

ROP is an important and potentially avoidable cause of blindness in children, which seems to be increasing in middle-income countries. In several countries it is the leading cause of childhood blindness. This disease is likely to become a problem in urban centres of low income countries as neonatal intensive care services are introduced.

Very little is known about the incidence of ROP in Indonesia, information which is important to plan screening and treatment strategies aimed at preventing blindness in childhood in Indonesia.

This is an extended study of a previously single Blind School study (10), showing relatively the same results on the prevalence of ROP as the causes of blindness. We found that ROP was not the major avoidable cause of childhood blindness. Our finding shows a low frequency of blindness due to ROP (1.1%), which may be an underestimation because of the high mortality rate of premature babies in rural centers due the lack of neonatal intensive care units. The results are in accordance with other studies of children in Blind School in China (5), India (7), and Sri Lanka (6). The Blind School in South Africa (11) 10.6% of blindness were due to ROP, but of this only 1.25% were of black population.

There are at least five tertiary health cares with neonatal intensive care units located in the five provinces in Java, which serve for the community in Java. Lack of a referral system for high risk mothers and / or premature or low birth weight babies from health care centers in rural areas to the tertiary specialist centers may contribute to the high mortality rate of premature babies.

However, ROP is not uncommon in urban centers in Indonesia where neonatal care facilities do exist. A separate hospital-based study in premature babies at Cipto Mangunkusumo Hospital, a tertiary referral center in Jakarta, Indonesia showed an incidence of ROP at any stage in 30.8% of premature infants (Adriono, Elvioza, Sitorus, 2006, in press).

Our study supports the notions that ROP remains a problem for all but the poorest population such as rural communities without neonatal intensive care units. This finding highlights the need for a better interaction between primary and secondary health care and the specialist tertiary centers (with their intensive neonatal care

services), to provide high coverage referral access for high risk mothers and / or premature or low birth weight infants. This strategy, coupled with development of excellent neonatal intensive care facilities, may lead to an increasing survival rate of this group of high risk babies. Finally, establishing guidelines for adequate screening programs and treating ROP in due time by pediatric ophthalmologists and retina specialists is essential to decrease the burden of this potentially avoidable cause of blindness in Indonesia.

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