

**Magnitude and temporal trends in avoidable blindness in children (ABC) in India**

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## **Abstract**

### **Background**

The World Health Organization estimates that 19 million children are visually impaired among whom, 1.4 million are blind.

Childhood blindness is an excellent indicator of the state of child health and primary care services in a country.

Childhood blindness is important not just due to the number of children blind but also because the number of years that the surviving child has to live with blindness (blind years lived). Childhood blindness is next only to adult cataract in terms of the number of blind person years lived.

Under-five mortality rates have been used as a proxy measure to compute the prevalence of childhood blindness in low and middle-income countries due to limitations of other methods of data collection. In India, it is estimated that there are 0.8 blind for 1000 children.

### **Objective**

Review the magnitude and temporal trends in avoidable blindness in children, with reference to the Indian context

### **Methods**

Review of published literature on blindness and visual impairment in children from India and other countries in the South Asia region were assessed and observations compiled.

### **Results**

Whole globe lesions, corneal scarring, retinal pathology and affections of the lens are important anatomical sites in children. Causes operating in childhood and hereditary causes are important in etiology of childhood blindness. In 38.2% - 68.4% across the region a specific cause of blindness could not be identified in South Asia.

### **Conclusions**

The proportion of blindness that can be prevented or treated (avoidable) in children is less than 50%. Therefore a comprehensive eye care system needs to be in place to cater to the needs of children with avoidable and those with

incurable blindness. Early detection and prompt management are critical for success of programs targeting avoidable blindness in children.

**Keywords**

Blindness; Childhood; India; Prevalence; Vision disability

## **Background**

The World Health Organization (WHO) defines childhood blindness and visual impairment as best corrected visual acuity of  $< 3/60$  (blindness) and  $< 6/60$  to  $3/60$  (visual impairment) in the better eye among those aged 0-15 years [1]. WHO estimates of the global magnitude of childhood blindness suggest that there were 1.42 million children blind and 17.52 million children with moderate or severe visual impairment. Thus 18.94 million children are visually impaired [2]. The global estimates show that childhood blindness is responsible for 3.64% of all blindness in the recent past [2]. These numbers do not capture the critical importance of childhood blindness because the number of years that a child lives with blindness compared to an adult is far more, which is why blind children deserve special attention. This has led to the concept of 'blind years' and 'blind years saved' [1]. It has been computed that childhood blindness results in 11.2 million blind person years as compared with 22.5 million blind person-years for age-related cataracts and 5.5 million blind person-years for glaucoma in India [3]. Some authors have highlighted that restoring the sight of one child blind from cataract is equivalent to restoring the sight of 10 older adults blind from cataract [1].

Loss of vision has a significant impact on the affected child's psychological, educational and socio-economic consequences spanning not only the childhood years but the years beyond too [4]. Visual impairment in children can present either as an isolated impairment or else it could be accompanied by other sensory or motor impairments.

Another important aspect that needs attention is that unlike overall causes of blindness where 80% are 'avoidable' (either preventable or treatable) [1], in children less than 50% of the causes are avoidable [5]. It is for this reason that childhood blindness is one of the five priority areas for augmented interventions that have been flagged up in the Vision2020: The Right to Sight initiative [6]. This also means that the proportion needing rehabilitative services are significantly higher in blind children compared to adults.

Childhood blindness is an excellent indicator of the state of child health and primary care services in a country. Studies have shown that the prevalence of childhood blindness is associated with socio-economic development of a country and the under-five mortality rate [5]. Using under-five mortality rates as a proxy measure, it has been possible to estimate the prevalence of childhood blindness across different regions of the world [7].

## **Measuring Blindness and Visual Impairment in Children**

Measuring visual acuity in children is a difficult proposition [7]. As blindness in children is relatively rare, accurate prevalence data are difficult to obtain, because very large samples are required for population-based prevalence surveys [5]. In addition, many of the causes of childhood blindness are also the causes of mortality in children and this leads to increased mortality of blind children either from the systemic complications of the blindness-causing condition or lack of adequate parental care and support [5]. It is therefore believed that the estimates of prevalence grossly underestimate the extent of the true incidence of childhood blindness [5]. This has resulted in other methods being used to assess blindness. In high income countries, population-based registers for visual impairment are used to compute the prevalence and magnitude of blindness in children [8]. Childhood vision screening and active surveillance have also been adopted in such countries [9]. In the low and middle income countries, alternative affordable methods have been used. These include the use of under-five mortality rates as a useful proxy measure for estimating childhood blindness, data from community-based rehabilitation (CBR) programs and through use of key informants from the community after a short orientation [10]. The key informant method has been used extensively in Bangladesh [10,11], Zambia [12], Malawi[13] and Nigeria [14].

## **Magnitude in India**

An estimated 19 million children are visually impaired worldwide of whom 1.4 million are blind [2,4]. In high income countries, the annual cumulative incidence of severe visual impairment and blindness is estimated to be 6/10,000 children by age of 15 years [4]. Such data is not available for low and middle income countries (LMIC) like India where socio-economic development and under-five mortality rates have been used to compute a prevalence of 0.3/1000 children in high income countries to 0.6/1000 in middle, 0.9/1000 in low income and 1.2/1000 in very low income countries [7]. The National Program for Control of Blindness uses an estimate of 0.8/1000 children as a reasonable projection for childhood blindness India [15].

Population-based data on childhood blindness is available only from a few studies in India and the neighboring countries in South Asia (Table 1). Estimates of blind children vary from 0.5/1000 children to 1.06/1000 children in India [3,16-22]. However the definition of blindness (presenting vision versus best corrected vision), method of collecting data (single stage where all children are examined in the community as against two-stage process where the first vision examination is done in the community and a detailed examination at a base hospital after referral) and

the age group covered are not uniform across the studies and therefore comparison of estimates is strictly not warranted. In some studies the primary purpose was not the estimation of childhood blindness but the estimates could be computed from the data.

### **Causes of Childhood blindness**

The two commonest sources for information on causes of blindness in children are population-based surveys and an assessment of children residing in schools for the blind. The causes vary based on the source. Population-based surveys show that refractive errors and amblyopia are important causes of childhood blindness [3,16] but the picture which emerges from inmates of schools for the blind is very different. A series of studies have been done in South Asia at schools for the blind over the last three decades and these have all used a standardized reporting format which was designed by the WHO [23]. This allows temporal trends to be computed and for comparisons to be made across regions and time periods. Data from the schools for the blind have a limitation that it is only a small segment of the population of children who go blind, that would be admitted to such institutions. This is because most of these institutions are located in urban areas and parents may not be comfortable to send their children, especially the girls to a distant location. Also as was mentioned earlier, a significant proportion of blind children, do not survive and therefore would not be represented in these institutions. The other limitation is that the event leading to visual loss generally would have occurred some years ago and recall bias would be encountered. One therefore sees that the exact location or the specific etiology causing vision loss may remain undetermined. Despite these limitations, data on causes of blindness from schools/institutions for the blind are the major source on causes of blindness in children.

The WHO format has been designed to record the causes of visual loss with an emphasis on preventable and treatable causes so that appropriate control measures can be planned and implemented [23]. The format captures information on the anatomical site affected and the etiology of the visual loss and data is also presented for both domains.

A review of studies from the schools for the blind in South Asia, reveal significant variations across regions/countries as well as over time in anatomical site of blindness [24-34]. Whole globe lesions seem to be higher in India compared to the neighboring countries in South Asia and this seems to have increased over time (Table 2). Microphthalmos, anophthalmos and phthisis are the commonest whole globe afflictions in the region. Corneal conditions were also recorded as a leading cause of blindness across the region. In the past, corneal scarring was

recognized as the single most important cause of childhood blindness [5]. Recent studies in India and Sri Lanka document a decreasing trend in corneal blindness. Evidence from India show that from a quarter of all blindness was attributed to corneal conditions earlier which is now down to around 10% [24-26; 29,30,33]. Staphyloma and corneal scarring were the commonest corneal conditions recorded. The lens and retina were other important sites causing blindness. Studies from India revealed a low proportion of blindness due to Retinopathy of Prematurity (ROP) [26,27,30], while more than 10% was attributed to ROP in Sri Lanka [32]. Globally ROP is recognized as a leading cause of childhood blindness especially in rapidly emerging economies [5].

Determination of the etiological cause in studies in South Asia showed that no etiology could be identified in 38.2% to 68.4% across the region (Table 3) [24-28; 30-34]. This is because of the high degree of recall bias in such an assessment. Causes operating in childhood and hereditary causes were the predominant attributable causes of childhood blindness. A low proportion of childhood causes (2.6%) and a high proportion of hereditary causes (37.5%) observed in Sri Lanka is a good indicator of what India can expect with improving child survival and primary health care programs [32]. Vitamin A deficiency and measles were the commonest childhood causes documented and with improved health care services and access a major reduction in these conditions is imminent in India also.

### **Implications of recent data on childhood blindness**

In South Asia it has been observed that the proportion of avoidable causes of childhood blindness varies between 28.8% - 69.2% [24-34]. Studies over the past decade in India document that avoidable causes are responsible for less than a third of childhood blindness [29,30,33]. Only one study from North East India shows that the proportion avoidable is 50% [27] (Table 4). Earlier studies in India (Table 4) showed a much higher prevalence of avoidable causes compared to the recent studies. This temporal change reflects success of primary health care interventions like immunization and supplementation programs which have made an impact on blindness attributable to vitamin A deficiency, measles, harmful traditional practices, rubella etc. This trend is supported by evidence which shows that there has been a significant reduction of vitamin A deficiency in India over the past few decades as shown by the reduction in the prevalence of Bitot's spots (which is indicative of vitamin A deficiency) from 1.8% among preschool children in 1975 to 0.2% in 2012 [35].

Over the past decade, both infant mortality rate and under-five mortality rate in India have decreased significantly [36]. Since under-five mortality has been found to be associated with childhood blindness rates, this should impact the magnitude of childhood blindness. Under-five mortality has reduced by 67% between 2005 and 2015 as shown by the National Family Health Surveys [36]. Concerted action was initiated to expand services for sick and preterm newborn infants in India which is reflected in the decreasing child mortality rates [37]. At the same time there has been an increasing prevalence of preterm births which brings in new challenges. An estimated 15 million babies are born preterm (<37 weeks of completed gestational age) each year and at least 32 million babies are small for gestational age [38]. In India, it is estimated that there were 3.52 million preterm births in 2010 [38]. The improved neonatal care services have resulted in better survival of pre-terms due to improved respiratory support, including the use of oxygen. ROP is especially sensitive to the quality of neonatal care, including appropriate, well-monitored oxygen [39]. India accounted for 10% of the worldwide estimate of blindness and visual impairment due to ROP in 2010 [38]. It has been stated that , unless scale-up of neonatal services are coupled with improvements in implementation of standards for high quality care and detection and treatment of ROP, the number of children surviving preterm birth with visual impairment secondary to ROP will continue to increase [39].

### **The Way Forward**

Childhood blindness is a condition where an integrated care approach is imperative. The mantra for success is forging partnerships between pediatricians and child care teams on the one hand and ophthalmologists and the eye care teams on the other. Early detection and referral will be from a pediatrician or primary care setting while a multi-disciplinary approach coordinated by an ophthalmologist is needed to manage the underlying cause of visual impairment and to optimize the child's development and social inclusion.

Further investments in neonatal care services and practices will yield excellent returns. India is now one of several LMIC experiencing the 'third epidemic' of blindness due to ROP [37]. Blindness due to ROP can be prevented by following an evidence-based screening protocol, detecting ROP in pre-threshold stage and providing time-bound treatment [37]. This approach has to be rigorously followed if blindness free survival of preterm babies is to be ensured in the country. Efforts are being made to build capacity for early screening of ROP at sick newborn care units and timely management to prevent visual impairment. The Queen Elizabeth Diamond Jubilee Trust is supporting the development of innovative approaches for screening and management of ROP in 5 states in India. If this approach is successful it can be scaled up to the rest of the country and may be useful for other LMICs also.



Primary health care is critical to the reduction of the preventable causes of childhood blindness. Improving coverage rates of immunization, introduction of the rubella vaccine, quality antenatal care provision and attention to nutrition will have an even bigger impact on childhood blindness.

With reduction of preventable causes, there will be a relative increase in the proportion of unavoidable causes of childhood blindness. These children need rehabilitative support including affordable and acceptable low vision devices. Therefore comprehensive eye care services which include a gamut of preventive, promotive, curative and rehabilitative interventions and innovations in detection and service delivery are the need of the future. Augmenting the available infrastructure for pediatric eye care at the specialty level is also important so that case detection is matched with appropriate services. Creating a demand without adequate service delivery networks is detrimental in the long run. Some people have been advocating for universal eye screening. Caution is required before such a step is taken as the currently available resources including human resource capacity and infrastructure needs to be scaled up in the first instance. The WHO has set norms for low vision services and pediatric eye care units for every 10 million population. Such norms need to be enforced to achieve pragmatic reduction in avoidable blindness in children and provide services for those in whom blindness and visual impairment could not be prevented or treated.

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**Table I****Prevalence of Childhood Blindness**

<b>Location</b>	<b>Age Group</b>	<b>Sample (n)</b>	<b>Year</b>	<b>Method</b>	<b>Visual Acuity</b>	<b>Visual Acuity cut-off</b>	<b>Prevalence per 1000</b>	<b>Reference</b>
West Godavari district, Andhra Pradesh	≤ 15 years	113,514	1996	Survey	BCVA <sup>†</sup>	< 3/60	0.65	3
Kariapatti, Tamilnadu	≤ 15 years	10,605	2000	2 stage survey	BCVA	<3/60	0.62	16
Andhra Pradesh	≤ 15 years	2861	2001	Survey	PVA <sup>‡</sup>	< 3/60	1.0	17
New Delhi, India	5-15 years	5950	2001	Survey	BCVA	< 6/60	0.5	18
Mahbubnagar, AP	7-15 years	3994	2001	Survey	BCVA	<6/60	1.3	19
Karnataka	≤ 15 years	13,241	2004	2 stage survey	BCVA	<3/60	1.06	20
Tumkur, Karnataka	≤ 15 years	23,100	2006	2 stage survey	BCVA	<3/60	0.8	21
Rajshahi, Bangladesh	≤ 18 years	8120	2013	Survey	PVA	<3/60	0.5	22

<sup>†</sup>BCVA – Best Corrected Visual Acuity; <sup>‡</sup> PVA – Presenting Visual Acuity

**Table II: Anatomical Site of Affection in blind children in schools for the blind**

Site	9 States, India	AP	Delhi	NE India	Bangladesh	Maharashtra	Karnataka	Myanmar	Sri Lanka	AP	Nepal
Reference	24	25	26	27	28	29	30	31	32	33	34
Year	1993	1999	2001	2004	2005	2005	2006	2007	2009	2009	2011
Examined	1318	291	650	376	1935	1985	1179	208	206	113	778
Whole Globe	25.3	20.2	27.4	31.8	13.1	46.3	44.9	19.2	18.3	41.4	16.7
Cornea	26.4	24.3	21.7	36.4	26.6	11.7	7.2	43.6	7.8	8.1	22.8
Lens	12.3	7.9	10.9	10.9	32.5	6.0	14.1	14.4	10.9	9.9	17.6
Retina	20.7	31.1	15.1	5.8	12.7	11.2	20.3	7.4	35.9	18.9	18.4
Optic Nerve	5.9	4.9	10.6	5.4	8.0	4.6	4.4	4.0	10.9	5.4	8.7
Uvea	5.8	3.4	8.8	2.3	2.0	1.5	0.3	2.5	2.6	4.5	5.0
Glaucoma	2.6	6.7	4.9	4.3	4.3	1.6	1.9	7.4	4.1	8.1	8.1
Others	0.9	1.5	0.8	3.1	1.0		10.5	3.0	8.8	10.8	2.7

**Table III: Etiological Classification of Causes of Blindness in South Asia**

Site	9 States, India	AP	Delhi	NE India	Bangladesh	Karnataka	Myanmar	Sri Lanka	AP	Nepal
Reference	24	25	26	27	28	30	31	32	33	34
Year	1993	1999	2001	2004	2005	2006	2007	2009	2009	2011
Examined	1318	291	650	376	1935	1179	208	206	113	778
Hereditary factors	22.9	34.8	13.4	7.0	15.0	44.1	11.9	37.5	17.1	27.9
Intrauterine factors	1.8	0.4	0.9	1.6		4.8	4.5	2.1	0.9	2.6
Perinatal factors	1.4	2.6	1.2	1.2		1.1	6.9	14.0	5.4	1.5
Childhood factors	27.9	24.0	28.0	38.4	27.9	8.6	33.2	2.6	8.1	22.0
Unknown etiology	46.0	38.2	56.5	51.9	41.4	41.3	43.6	43.8	68.4	46.0



**Table IV: Avoidable causes of blindness among children in South Asia including India**

Site	9 States, India	AP	Delhi	NE India	Bangladesh	Maharashtra	Karnataka	Myanmar	Sri Lanka	AP	Nepal
Reference	24	25	26	27	28	29	30	31	32	33	34
Year	1993	1999	2001	2004	2005	2005	2006	2007	2009	2009	2011
Examined	1318	291	650	376	1935	1985	1179	208	206	113	778
<b>Total Avoidable</b>	47.3	37.4	43.5	50.1	69.2	34.5	29.5	43.6	36.5	28.2	40.9
<b>Preventable</b>	31.0	19.8	28.0	34.5	27.3	22.2	10.1	27.3	5.7	12.6	23.1
VAD <sup>†</sup> / Measles/ Staphylooma/ Scar	21.8	19.1	21.4	34.5	23.8	-	10.1	17.4	-	1.8	11.6
TORCH/ meningitis	4.6	-	3.4	-	1.6	-	-	-	0.5	-	2.6
Trauma / HTM <sup>‡</sup>	1.3	0.7	1.7	-	1.2	-	-	2.5	2.1	3.5	7.4
Others	3.3	-	1.5	-	0.7			7.4	3.1	7.3	1.5
<b>Treatable</b>	<b>16.3</b>	<b>16.1</b>	<b>15.5</b>	<b>15.6</b>	<b>41.4</b>	<b>12.3</b>	<b>19.4</b>	<b>16.3</b>	<b>30.8</b>	<b>16.2</b>	<b>17.8</b>
Cataract	12.3	7.9	8.3	10.1	32.5	-	14.1	11.4	8.4	2.7	6.5
Glaucoma	2.8	6.7	4.9	4.3	4.3	-	1.9	4.9	4.2	8.0	8.1
Uveitis		1.5	1.8		1.1	-	0.2	-	0.5	4.4	0.5
ROP	0.2	-	0.5	0.8	-	-	0.2	-	12.5		
Others	1.0	-	-	0.4	3.2	-	3.0	-	5.2		2.7

<sup>†</sup> Vitamin A deficiency; <sup>‡</sup> Harmful traditional practice