



A World Without Childhood Blindness

The GAPIO Collaboration with Eye Foundation of America

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Background

Very little data is available on the prevalence of childhood blindness from population-based studies. Prevalence and incidence data from blind registers underestimate the figure because of under-reporting. Globally, the prevalence of blindness among children is estimated to be approximately one-tenth of that in adults, at around 0.7 per 1000. However, blindness in childhood has far-reaching implications for the affected child and family, and throughout life, profoundly influences educational, employment, personal, and social prospects.¹ A World Health Organisation meeting on Childhood Blindness in 1990 estimated that there were approximately 1.5 million blind children worldwide, of which 90% live in developing countries. It was also estimated that about 500,000 children go blind each year worldwide, of which 60-80% die within the subsequent 1-2 years from the diseases which contributed to their blindness or from neglect consequent upon being blind. The prevalence of blindness in children is closely related to the availability of health care for children (nutrition, immunisation etc.) and, therefore, to child survival and under-five mortality rates (U5MR). Countries

with high U5MR (over 170/1000) are likely to have a prevalence of childhood blindness over one per thousand, while those countries with low U5MR (below 30/1000) probably have a prevalence of between 0.2--0.5/1,000 children.² The only data on the incidence of childhood blindness come from blind registrations in developed countries. Robinson reviewed the prevalence of congenital blindness in British Columbia from 1945-1984, showing a reasonably constant figure for congenital blindness of 4/100,000 births from 1955-80. From the population survey in India, from a cohort of over 6000 children, the prevalence of childhood blindness was estimated to be 0.17% (95% confidence interval 0.09 to 0.30).³

Childhood Blindness

In a study from the Republic of Ireland, 56% of children had lesions due to factors acting before the perinatal period (genetic causes), 27% had lesions due to factors acting in the perinatal period (birth asphyxia and prematurity), and 13% had lesions due to factors acting in childhood.⁴ In a study from Southern India, a treatable refractive error caused 33% of blindness, followed by 17%

due to preventable causes (8% each due to vitamin A deficiency and amblyopia after cataract surgery). The major causes of the remaining blindness included congenital eye anomalies (17%) and retinal degeneration (17%).³ Microphthalmos, retinitis pigmentosa, optic atrophy, and cataracts were the leading causes of childhood blindness.⁵ Childhood blindness has a far more significant impact on the individual and the society compared to adult blindness considering the total number of disability-adjusted life years lost (the number of years that a blind person lives after going blind), the difficulty in integrating the child socially and functionally, and the long-term burden on the caregiver and society. The World Health Organization (WHO) chose childhood blindness as one of the five avoidable ocular conditions under the VISION 2020-Right to Sight initiative. In India, the initiative has been clubbed under the National Program for Control of Blindness (NPCB), and numerous measures have been started. These include setting up and upgrading paediatric ophthalmology units, school screening programs, and providing facilities for refraction and low-cost spectacles in children.⁶

Controlling childhood blindness was a priority of the World Health Organisation's (WHO) global initiative to eliminate avoidable blindness by 2020.⁷ Since VISION 2020 was launched in 1999, controlling blindness in children has been a high priority. Child Eye Care Centres are being established with trained, equipped teams, particularly in Asia. Programmes for detecting babies with retinopathy of prematurity (ROP) are expanding in Latin America, India, China, and other countries in Asia. Many school-going children are having their visual acuity measured, and those with a refractive error are being provided spectacles. Finally, there is improved availability of affordable consumables and equipment, such as paediatric low-vision devices, small-diameter intraocular lenses, and spectacles for children.

However, the goal of eliminating avoidable blindness in children (ABC) is still some distance away. In 1977, while living in London, the author returned to India with personnel and equipment. He offered his first eye camp to remove cataracts, and synthetic implants replaced prescription

glasses. The purpose of an eye camp is to provide patients living in remote areas the opportunity to receive quality, inexpensive treatment that would otherwise be unavailable. Eye camps have been organised, managed, and conducted on a "crash-program" basis as the only practical way of reaching cataract patients. Without any reason-able alternative, the eye camp concept seems to be the only piratical method of bringing visual relief to rural Indians.⁸ While there are benefits of outreach facilities via eye camps, and outcomes may be similar, there are some disadvantages - such as loss of follow-up, which eventually affects the management of amblyopia and postoperative complications.⁹

Eye Foundation of America

The West Virginia Ophthalmology Foundation was created in 1982 and became the Eye Foundation of America (EFA) in 1992. The EFA's mission is to eliminate avoidable childhood blindness around the world.¹⁰ The EFA operated on three guiding principles: service, teaching, and research. Collaboration among medical practitioners,



Eye camp in Vijayawada 1979

trainees, and researchers from the United States and developing countries was crucial to accomplishing the EFA's mission. Medical care was provided free of charge. The EFA not only trains medical practitioners to join the global fight

against blindness but also instructs school teachers on how to screen for early eye problems in children and educates the public on eye care and prevention. Research is critical to determine the best and most efficient ways to implement strategies that will further the EFA's mission.

In the late 1970s, surgical eye camps were in vogue in India. During this era, in addition to the hundreds of screening camps it held, some organisations set up a few surgical eye camps, which proved to be very resource intensive. In these surgical camps,

operations were performed at the site: a school, a college, a community hall, or a local hospital. Intracapsular cataract extraction (ICCE) was the surgical procedure at that time. The postoperative stay at the campsite ranged from four to seven days. Patients had to lie down with their eyes bandaged in a complete resting position to avoid wound leak or iris prolapse, and they were given soft food to eat. The operated patients were issued standard +10 D aphakic spectacles at discharge and advised to come for follow-up at the base hospital or campsite a month later. The model has shifted to screening camps and operations done in fixed, state-of-the-art facilities.¹¹ Community ophthalmology encompasses a broad spectrum of components that can supplement the delivery of eye care: Creating awareness of eye health in the community through various strategies, conducting epidemiological research and community-based surveys, planning and management of sustainable eye care services, integration of critical components such as school children screening, community-based rehabilitation, and primary eye care and training of primary eye care workers.¹² There are many risks to consider when offering eye care services outside of established eye care facilities. Risk assessment and careful planning keep patients, staff members, and community members safe.¹³

Accessibility & Sustainability



The World Bank claims that combatting childhood blindness is the single most cost-effective health intervention. These services are often rendered through travelling eye camps and permanent hospitals built by the EFA, including the Gautami Eye Institute^{10,17} in rural India. Parents, their families, and the more significant communities benefit from preventative medical care, free procedures, and access to education. By

preventing avoidable blindness in children, such initiatives give the gift of 75+ years of a whole and productive life.

The most effective way to reach fringe or rural outreach communities is to train and integrate primary eye care workers into the existing primary health care systems. Ideally, a resident of these communities is identified and prepared for this work — what most projects call a community-based rehabilitation (CBR) worker. These primary eye care workers are best placed to penetrate the 100-metre barrier around a blind person's home.¹⁴

Most health systems still need help implementing Comprehensive Eye Care, mainly due to political, economic, and logistic barriers. Shortage of eye care human resources, lack of educational skills, paucity of funds, limited access to instrumentation and treatment modalities, poor outreach, lack of transportation, and fear of surgery represent the significant barriers to its large-scale diffusion. In most low- and middle-income countries, primary eye care services are defective and must be more adequately integrated into primary health care and national health systems. Social, economic, and demographic factors such as age, gender, place of residence, personal income, ethnicity, political status, and health status also reduce the potential for success of any intervention.

Cost-effectiveness analysis of outreach eye camps shows that they can be time-consuming for the ophthalmologist and only result in net profit for the institution if the ophthalmologist converted most cataract patients into accepting surgery and refractive error patients into purchasing glasses from the hospital optical shop. Such a model of cataract surgery programs must reduce the cost of imported consumable surgical products, reduce operation time, and, most importantly, reduce the number of very costly surgical camps providing essentially free surgery.¹⁵ Practitioners often adopt strategies to improve the sustainability of their services by maintaining 'sustainability funds' to retain financial autonomy over income; avoiding granting government user fee exemptions to elderly patients who are the majority of service users; expanding or contracting outreach services

as economic circumstances change; and accessing peer support for problem-solving and advocacy.¹⁶

Goutami Eye Institute and the EFA

Goutami Eye Institute and the EFA have facilitated 700+ physician exchanges and over 340,000 eye surgeries, 30,000 eye surgeries on children, and the treatment of 3.5 million outpatients since the inception of the Eye Foundation of America.



The child operated on for bilateral cataracts

Future Opportunities

With the collaboration of the Global Association of Physicians of Indian Origin, the EFA will continue to offer eye camps in more than 35 developing countries, train medical personnel to serve the needy and educate the population on preventative eye care and healthy lifestyle choices. In addition to constructing a new Goutami Eye Institute, which has a wing dedicated to children, the EFA is adding a secondary service and research hospital in India where no child will be denied treatment and children from around the world can come to receive world-class services. The EFA are also committed to finding new cures for age-old eye

diseases in children. The EFA operates on donations. However, more money, qualified people, pharmaceuticals, and state-of-the-art equipment are always needed. By focusing on prevention, education, and supporting primary medical services in developing countries, the potential is limitless. It embodies the concept of ways to do more with less.

Conclusion

The Lancet Global Commission on Global Health reported that in 2020, an estimated 596 million people had distance vision impairment worldwide, of whom 43 million were blind. Another 510 million people had uncorrected near vision impairment simply because of not having reading spectacles. Many affected (90%) live in low-income and middle-income countries (LMICs). However, encouragingly, more than 90% of people with vision impairment have a preventable or treatable cause with existing highly cost-effective interventions. Eye conditions affect all stages of life, with young children and older people mainly affected. Crucially, women, rural populations, and ethnic minority groups are more likely to have vision impairment, and this pervasive inequality needs to be addressed. By 2050, population ageing, growth, and urbanisation might lead to an estimated 895 million people with distance vision impairment, of whom 61 million will be blind. Action to prioritise eye health is needed now.¹⁸

Vision facilitates many daily activities, enables better educational outcomes, and increases work productivity, reducing inequality. An increasing amount of evidence shows the potential for the image to advance the Strategic Developmental Goals by contributing towards poverty reduction, zero hunger, good health and well-being, quality education, gender equality, and decent work. Vision loss has many causes that require promotional, preventive, treatment, and rehabilitative interventions. Cataracts, uncorrected refractive error, glaucoma, age-related macular

degeneration, and diabetic retinopathy are responsible for most global vision impairments. Research has identified treatments to reduce or eliminate blindness from all these conditions; the priority is to deliver treatments where they are most needed.

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