

Eye conditions and blindness in children: Priorities for research, programs, and policy with a focus on childhood cataract

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The major causes of blindness in children encompass intrauterine and acquired infectious diseases, teratogens and developmental and molecular genetics, nutritional factors, the consequences of preterm birth, and tumors. A multidisciplinary approach is therefore needed. In terms of the major avoidable causes (i.e., those that can be prevented or treated) the available evidence shows that these vary in importance from country to country, as well as over time. This is because the underlying causes closely reflect socioeconomic development and the social determinants of health, as well as the provision of preventive and therapeutic programs and services from the community through to tertiary levels of care. The control of blindness in children therefore requires not only strategies that reflect the local epidemiology and the needs and priorities of communities, but also a well functioning, accessible health system which operates within an enabling and conducive policy environment. In this article we use cataract in children as an example and make the case for health financing systems that do not lead to 'catastrophic health expenditure' for affected families, and the integration of eye health for children into those elements of the health system that work closely with mothers and their children.

Key words: Child health policy, childhood blindness, social determinants of eye health

Over the past 20 years it has become apparent that the prevalence and pattern of causes of blindness in children are dynamic; changing in response to socioeconomic development and the extent to which public health programs for child health are being implemented and accessed by communities.^[1] In the industrialised world the major causes of blindness predominantly affect the retina and higher visual pathways, with prematurity being an important underlying cause.^[2] Many children in these settings have other disabilities.^[2] In the poorest countries of the world, systems, including health systems, are often dysfunctional on account of civil unrest or for economic or political reasons. In these settings female education is also low and the prevalence of blindness in children may be 4–5 times greater than in well-resourced countries. In these extremely underdeveloped economies, demographic differences mean that there may be ten times as many blind children per head of population as in well resourced countries. Causes in very poor countries reflect inadequate control of measles and vitamin A deficiency, as well as lack of services to detect and manage treatable causes such as cataract.^[1]

The picture is different again in the middle-income countries of Latin America and Eastern Europe where blindness due to retinopathy of prematurity (ROP) is often the single most common cause of blindness.^[3] Many countries in Africa and Asia have effective programs in place for measles and

vitamin A deficiency, and in these settings cataract is often the most common avoidable cause.^[4] In countries with rapidly improving economies and development the causes of blindness reflect these changes. For example, a large population-based study in Vietnam which included almost 30,000 children, together with the examination of children in virtually all the schools for the blind in the country, demonstrated that older children were more likely to be blind from corneal scarring due to vitamin A deficiency while younger children were more likely to be blind from ROP,^[5] reflecting the rapid and marked socioeconomic changes in the country since the mid 1980s. In India, the pattern of causes is also likely to vary between States, with poorer states having a higher prevalence of blindness and a different pattern of causes than States with higher economic development, and health indicators. However, evidence to confirm this is currently limited in the absence of population-based data.

The distal risk factors that influence child health in general, and child eye health in particular, encompass the socioeconomic and demographic. As the economies of many countries continue to improve, the major causes of avoidable visual impairment will also continue to change.^[6] Retinopathy of prematurity is likely to become a major cause in India and China, as these countries expand provision for neonates and preterm babies,^[7] while cataract will continue to overtake corneal scarring as the major avoidable cause in the poorer countries of Asia and Africa. Emphasis therefore needs to be placed on initiatives and programs for the control of blindness from ROP and cataract in children.

But what about other eye conditions of childhood? Once again the prevalence, incidence, and pattern of causes vary, with countries in South East Asia, China in particular, having an extraordinarily high prevalence of myopia.^[8] There are estimated to be over 100 million children with active trachoma, mainly in sub-Saharan African countries, but in Africa the

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available evidence suggests that the prevalence of significant refractive errors is relatively low.^[9] There are other conditions which either cause ocular morbidity in their own right, such as vernal keratoconjunctivitis, or cause morbidity on account of the use of harmful traditional remedies or inappropriate and long-term use of topical steroids (e.g., for viral conjunctivitis or vernal keratoconjunctivitis). However, apart from a few isolated efforts, very few population-based studies have been undertaken to estimate the prevalence and type of ocular pathology among children.^[10]

Challenges in the Control of Cataract in Children

As cataract is the most common treatable cause of blindness in children in developing countries,^[4,6] the remainder of this article will focus on cataract. However, many of the issues apply equally well to other eye conditions of children.

Costs of Cataract Surgery in Children for Families

Unlike adult cataract surgery, which is increasingly performed as a day case, young children undergoing cataract surgery need to be admitted to hospital for several days as: (a) they require surgery under general anesthetic and need preoperative assessment the day before surgery; (b) children's eyes can become inflamed after surgery and so the child needs to be kept in hospital so that this can be treated; and (c) if a child is undergoing surgery on the first eye and the second eye is not operated on within a narrow time frame, the second eye will develop dense amblyopia. It is therefore usual practice for a child to be admitted for the first eye, and then to undergo surgery on the second eye a few days later, during the same admission. The child will only be discharged when it is confirmed that both eyes are recovering well from surgery. The entire in-patient stay is usually at least a week.

Direct, out-of-pocket expenditure for cataract surgery for children is therefore likely to include some or all of the following direct costs: hospital registration; surgical, anesthetic and inpatient fees; cost of the intraocular lens (IOL), which are usually more expensive than those used in adults; eye drops and spectacles, which again are often more expensive, as bifocals are usually required. Indirect costs will include travel for parent(s)/other adult(s) and the child, accommodation and food while away from home. Other indirect costs might include expenditure on the care of other children, land, or property while parents are away. Productivity losses are also likely, being incurred by spending time away from income generating activities. Children also require frequent follow-up and often require frequent change of spectacles, low vision devices, and even further surgery. All these costs will be considerable, particularly for poor families. Despite the plethora of studies that cite 'cost of surgery' as a barrier to access, there is very limited literature on the actual costs incurred by families,^[11] and on how they raise the funds, or on the impact this may have on households.

Household decision making in relation to accessing health services is complex, the first decision being that someone in the family is ill and needs health care. There is some evidence that families less readily perceive a girl to be ill than a boy, and

so health care is not sought.^[12] This may, in part, explain why virtually all studies in developing countries report that many more boys undergo surgery for bilateral cataract than girls.^[13-16] Other decisions require reliable information on likely costs, so families can decide if this is the best use of their scarce resources in terms of time as well as money. Indeed, uncertainty in itself is a considerable barrier as families do not know how much money to raise before they leave home. Other barriers to the uptake of surgical care for childhood cataract include fear of surgery or of a poor outcome, beliefs that congenital blindness cannot be cured, lack of information on available services and poorly educated mothers—all of which need to be addressed through counseling of parents. More training of health workers is also needed, as they often do not recognize the urgency of cataract in children and give parents the wrong advice.

Health Financing and 'Catastrophic Health Expenditure'

One of the outcomes of a good health system, as described in the World Health Organization's (WHO's) health systems framework, is a system which protects communities from financial risk.^[17] Protection can result from any mechanism which reduces out of pocket expenditure, such as health insurance schemes, government policies in relation to specific subsidies or other financing arrangements, and social franchising in health in the private sector.^[18] Each system has its advantages and disadvantages. In many parts of the world eye care is delivered extensively by the non-government organization (NGO) sector, where patients are charged for services. Many have a system of generating profit from those who can afford to pay so that the poor can be charged less, or not at all.^[19] However, these safeguards cannot take into account all the costs incurred in accessing services (e.g., transport and productivity losses are not included). Indeed, a recent study across five locations in India showed that the ratio of indirect:direct out of pocket expenditure for health care was 1:2.^[20] Evidence from a systematic review of the literature on the impact of different funding mechanisms on the attributes of the health system, indicates that user fees in India have a negative impact on use of services, equity in access as well as poverty alleviation (from <http://www.equitablehealthfinancing.org/about>).

One way of defining the term 'catastrophic health expenditure' is when out of pocket expenditure on health exceeds some proportion of household income or household expenditure, although there is no consensus as to what the proportion might be.^[21] Another way of assessing catastrophic health expenditure is in relation to the household's capacity to pay, and the consequences of raising/finding this money.^[22] For example, a recent study in India defined catastrophic health expenditure as 'that which reduces the nonhealth expenditure to a level where the household is unable to maintain consumption of necessities.'^[23] Catastrophic expenditure does not, therefore, always imply that the costs are excessively high as even a relatively low cost may constitute a high proportion of the household income of the poor. Particularly vulnerable groups in the US include households headed by an elderly person, people with disabilities, and the unemployed.^[21] In Bangladesh, a study explored costs incurred during hospitalization of children with pneumonia, showing that the mean expenditure of families was almost USD100. For 75% of families in this

study, this represented more than half of their total monthly expenditure.^[24] Three quarters of these families raised the money through borrowing, or by mortgaging or selling assets. Those borrowing repaid the loan with interest rates ranging from 5% to 30%. To repay their debts, 22% of families said they would work extra hours and 50% planned to reduce spending on food and the education of their children. In the Indian study, some households were spending almost eight times their monthly household income on health care. Chronic illnesses, although less common, accounted for almost one-third of the total expenditure.^[20] Despite an extensive literature on catastrophic expenditure in relation to many conditions and diseases, there is none on eye care in general, nor on eye care for children in particular.

There is an urgent need to ascertain the extent to which cost is a barrier to families of children with cataract. For families who do access services, it is important to know the extent to which they are impoverished by the direct and indirect costs, and to describe their productivity losses and coping mechanisms. The information will be of value in advocacy, resource mobilization, and in policy formulation. Indeed, it has been suggested that Millennium Development Goals 4 and 5 will not be achieved unless user fees for obstetric^[25] and child health services are removed and many countries are now implementing these policies to good effect.^[26]

An example of policy to reduce catastrophic health expenditure in relation to child eye health comes from Mexico. As part of their health system reforms, interventions that are highly cost effective but expensive are identified, user fees are waived, and the cost of treatment is borne by the government. In Mexico, laser treatment of ROP falls into this category.^[27,28] However, despite this policy being in place, programs for ROP in Mexico are not as advanced as they might be,^[29] and research is needed to explore the reasons why the policy is not being

fully implemented. Similar research would be needed should user fees for childhood cataract be waived.

Primary Eye Care and Child Health

There has recently been renewed interest in, and interest to improve primary health care as the bedrock upon which other services can be built.^[30] As WHO states, the rationale for this call is that 'health systems are developing in directions that contribute little to equity and social justice and fail to get the best health outcomes for their money'. The WHO has identified three factors which have contributed to this state of affairs: 'health systems that 1) focus disproportionately on a narrow offer of specialized curative care; 2) where a command-and-control approach to disease control, focused on short-term results, is fragmenting service delivery; and 3) where a hands-off or laissez faire approach to governance has allowed unregulated commercialization of health to flourish'^[30] [WHO, pg Xiii].

In terms of child eye health, lack of primary eye care means that children with cataract are not being detected early and visual outcomes are being compromised as a consequence. Different approaches to improving access to eye care services for children include outreach activities, school programs for the detection and treatment of refractive error, and short-term initiatives to train health workers who have responsibilities for children (e.g., Anganwadi workers in India) or those delivering immunization programs, or volunteers (e.g., Key Informants in Bangladesh,^[4] Malawi, China,^[31] etc.). However, despite the success of these initiatives they are unlikely to be sustainable, and coverage is limited. What is required is the integration of eye health for children into primary level child health initiatives and programs. For example, ocular prophylaxis for the prevention of ophthalmia neonatorum should be an integral part of the routine work of midwives:

Table 1: Priorities for research

Type of research	Areas of research for child eye health	How findings could be used
Health financing	Assessment of the impact of different health financing mechanisms on access to child eye care services and the extent to which they cause catastrophic health expenditure. Assessment of the impact of waiving user fees for children on access to services.	Policy Planning services which promote access and quality
Operational research	Integration of primary eye care for children into existing child health services and programs. Integration of eye health into school health.	Program development Policy
Policy research	Exploration of the players and factors which promote adoption of policies in relation to child eye health (e.g., for ROP screening and treatment in Latin America) as well as factors which influence whether policies are implemented, through case studies.	Policy development To support implementation of policy
Epidemiology	Population-based studies to estimate the prevalence and types of a range of eye conditions in different populations of children, for example, significant refractive errors, allergic eye disease, infections, strabismus, amblyopia, etc.	Priority setting Planning services at primary and secondary level
Community Development/health promotion	Participatory community-based studies to better understand perceptions and attitudes toward eye diseases of childhood, and decision making in relation to health seeking behavior.	Development of health promotion which reflects communities' perceptions and needs
Clinical research	Studies on the outcome of cataract surgery in children to identify how these could be improved. Studies on the need for, and impact of, low vision services, particularly among children following cataract surgery.	To improve services

it needs to be included in their training curriculum, supplies of sterile lid wipes and topical antibiotic or antiseptic should be maintained, and coverage and effectiveness needs to be monitored. Similarly, examination of the red reflex should be part of routine examination of the newborn as a means of detecting cataract, as has been adopted in Brazil (A. Zin, personal communication, 2012). Primary health care workers who have specific responsibilities for maternal/reproductive child health are potentially key players in the delivery of primary eye care for children, being able to play a promotive, preventive, and therapeutic role. Ideally these activities should be an integral part of training programs, with supportive supervision and systems in place to ensure regular supplies of essential medication, such as topical antibiotics, good health management information systems to monitor activities, and clear referral pathways for children needing further investigation or treatment. Preliminary studies in Dar es Salaam, Tanzania in 30 Reproductive and Child Health clinics across the city pilot tested materials based on the '10 key activities for healthy eyes'. Preliminary findings showed that the training and materials were well received; mothers found the posters interesting; diagnostic and management skills showed some improvement; health education sessions included eye health, and ocular prophylaxis was reinstated in several clinics.^[32] More research is needed in this crucial area of child eye health, ideally by fully integrating the training, supervision, monitoring, and reporting into government systems.

Although much has been achieved in terms of the delivery of eye care services for children, evidence is needed on how these could be improved, particularly in terms of access. Further research is needed in a range of areas and disciplines in addition to those outlined above. Table 1 summarizes some of the evidence gaps that need to be addressed, but this is by no means a comprehensive list.

If the avoidable causes of blindness in children are to be eliminated over the next 10 years or so, equitable access to services has to be dramatically improved.

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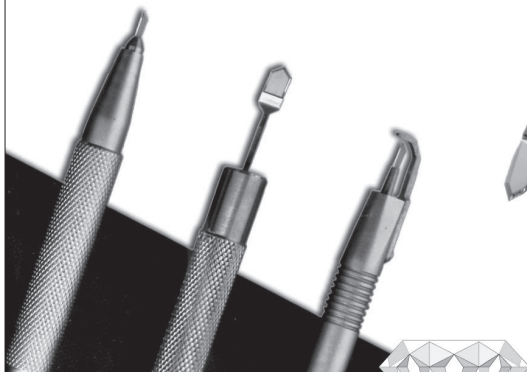
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