

Cataract Update

Childhood cataract in sub-Saharan Africa

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Abstract

Investment by organizations and agencies has led to a growing body of evidence and information to assist ophthalmologists and others to meet the needs of children with cataract in Africa. The geographic distribution of research, training, and programme development across Africa has been uneven; investment has been greatest in eastern and southern Africa. Population based surveys (using key informants) suggest that 15–35% of childhood blindness is due to congenital or developmental cataract. There may be up to 82,000 children with non-traumatic cataract in Africa, with approximately 19,000 new cases each year.

Effective strategies to find and refer children are those that engage the community in case detection. Identification and referral does not automatically mean surgical intervention with distance to the surgical facility being the most common reason for failure to seek care. Surgical management has become more specialized and a team based approach has been adopted by many paediatric ophthalmologists and their programmes. Although many children still present late for surgery, outcomes of surgery are much improved from previous experiences. Research suggests that post-operative follow up, still a challenge, can be improved through adoption of specific strategies. There has been limited success in ensuring that children are placed in appropriate educational settings. While eye care professionals may feel their responsibility ends with clinical care, it is important for the paediatric eye care team to be engaged with educational and rehabilitation services.

Keywords: Childhood cataract, Africa, Review

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doi:10.1016/j.sjopt.2011.10.006

Introduction

In the last 10 years childhood cataract has started to receive notice and investment in sub-Saharan Africa. As a result, there is a growing body of evidence and information to assist ophthalmologists and others to meet the needs of children with cataract. Unlike age-related cataract in adults, childhood cataract requires a more complex set of interventions to ensure that a child receives surgery in a timely fashion, obtains the best possible surgical outcome, and is visually rehabilitated. In the last decade much work has been carried out to better understand best practices for case detection, surgery, post operative care, and links to educational support and rehabilitation.

Cataract in children includes several different types. Traumatic cataract can be easily defined as the onset of

cataract following trauma to the eye. In most cases, traumatic cataract is unilateral and it rarely contributes to bilateral childhood blindness. That said, it cannot be ignored as traumatic cataract in children often represents a large proportion of cataract surgeries in children. Congenital cataract, by definition, refers to cataract present at the time of birth, but it may or may not be clinically obvious at birth. A more practical definition considers whether the visual axis was clear from birth until 12 months of age. If a child developed vision loss due to cataract within the first year of life, it is likely that visual pathways did not have an opportunity to develop properly. If a child had good vision through the first year of life and the cataract developed afterwards, then it is likely that the visual pathways developed sufficiently before the onset of cataract. The terms “congenital” and

Received 6 October 2011; accepted 27 October 2011; available online 7 November 2011.

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Peer review under responsibility
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Table 1. Findings from population based studies using key informants to find children with blindness and severe visual impairment.

Country (references)	Estimated prevalence of blindness (per 10,000 children) [children in surveyed population]	Primary causes of blindness
Malawi ³	7.8 [48,000]	Lens = 35%
Nigeria ⁴	1.6 [123,000]	Cornea = 22%
Tanzania ⁵	1.7 [95,000]	Cornea = 75%
Ethiopia ⁶	5.1 [136,000]	Lens = 15%
		Posterior segment = 31%
		Lens = 25%
		Lens = 33%
		Cornea = 28%
		Whole globe = 19%

“developmental” cataract are often used to denote onset of cataract related vision loss within the first year of life or after the first year of life, respectively. There have been no studies of the etiology of childhood cataract in Africa and the actual contribution of various putative factors, including rubella, although recognized to be present, have not been documented.

Globally, congenital cataract has been estimated to account for around 15–20% of all blindness in children.¹ This estimate was made at a point in time when the global estimate of childhood blindness in developing countries was estimated at 1/1000 children.² Extrapolating from this, it can be estimated that in 2011 there are about 82,000 children with congenital cataract among the estimated 410 million children (age < 16 years) in sub-Saharan Africa. With significant reductions in the prevalence of vitamin A deficiency related blindness it is unlikely that the magnitude of childhood blindness in sub-Saharan Africa remains at 1/1000 children. Recent African population based studies, mostly utilizing key informants, have suggested that the prevalence of blindness in children is likely to range between 0.2/1000 children and 0.8/1000 children (Table 1). In the population based studies all non-traumatic cataract (histories are often inadequate to determine if the cataract was congenital or developmental) has accounted for 15–35% of the blindness burden.^{3–6} In settings in which corneal causes still predominate, the proportion due to cataract often remains low. In Kilimanjaro,⁵

where active case finding has been carried out, the prevalence of blindness was low and only one child (of 13 children blind children) was found with unoperated cataract. The prevalence of non-traumatic cataract in children will vary considerably with some settings having very low prevalence and some settings (without services or programmes) having a higher prevalence. Findings from surveys in schools for the blind, while not providing information on prevalence, give some indication of causes; in recent schools for the blind surveys in Africa^{7–11} the proportion of children blind due to cataract ranges between 13% and 26% (Table 2).

Making an estimate of the prevalence on childhood blindness due to cataract across Africa should be approached with caution given the variation in service delivery and other, as yet, undetermined factors. Estimating incidence of non-traumatic cataract in children in Africa based on industrialized country data may not be reliable. There is good evidence that the incidence of non-traumatic cataract in children in Africa is higher than the incidence in industrialized countries, for a whole host of reasons. For the purpose of planning eye care services for children, it has been estimated that there are around 20 children born each year with congenital cataract in a total (all age) population of 1 million.¹² This would suggest that, across sub-Saharan Africa (population 932 million), there would be around 18,640 children born each year with congenital cataract.

Finding and referring children with cataract

There has been a growing body of evidence of effective strategies to find and refer children with cataract; most of these studies have been part of strategies to find and refer blind (or severely visually impaired) children with conditions that could be managed by surgery, optical correction, or rehabilitation. Prevailing evidence suggests that it is essential to engage with the community in order to identify children needing assessment.^{13,14} Qualitative research has demonstrated a number of reasons for this: parents may feel that there is no alternative to a life spent in blindness, either because they feel that no cure is available or that the condition is “the will of God”, due to some personal or family transgression.¹⁵ Equally important has been the fact that workers at peripheral health facilities have either tried to treat the condition themselves or have told parents to “wait until the child is older” before seeking eye care services. In many rural health settings in Africa front line health workers only interact with the community when people come to the health facility; there may be limited community-based activities by health workers. Thus, the successful programmes have been those that involve some form of direct intervention with the community; key informant methods, first introduced in Bangladesh,¹⁶ have been increasingly adopted in Africa. Findings from pilot studies in Tanzania and Malawi suggest that key informants are three times more likely than health workers to identify children with severe visual impairment or blindness. In the Tanzanian study 94% of children with non-traumatic cataract were identified by key informants rather than by front line health workers.¹⁴

It has long been recognized in Africa that identification and referral does not automatically mean surgical intervention; many children do not actually arrive at the surgical facility. Research has suggested that the most common reason

Table 2. Findings from recent schools for the blind surveys in Africa.

Country, year (references)	Number of children in survey	Primary causes of blindness
Malawi, Kenya, Tanzania, Uganda, 2009 ⁷	701	Cornea = 19%
		Whole globe = 15.7%
		Retina = 15.4%
		Lens = 13.1%
Nigeria, 2011 ⁸	30	Lens = 26.7%
		Glaucoma = 20%
		Retinitis
		pigmentosa = 16.7%
Ghana, 2008 ⁹	201	Cornea = 59.3%
		Lens = 23%
		Glaucoma = 15.6%
Cameroon, 2010 ¹⁰	56	Cornea = 32.1%
		Optic lesion = 26.8%
		Lens = 19.6%
Nigeria, 2009 ¹¹	45	Glaucoma = 22%
		Cornea = 20%
		Lens = 13.3%

for failing to reach the surgical facility is distance.¹⁷ Distance is a barrier for a number of reasons: the fear of traveling the long distance to reach the facility, the cost of transport and food and accommodation along the way (family member plus child), and the amount of time that family member will be away from the household. Research into delay in presentation suggests that decision making within the household also contributes; male family members generally have more decision making authority and may not be willing to allocate resources (including money and time).¹⁵ Mothers who have some education and resources of their own have been shown to be more empowered to bring in their children sooner.¹⁷

While the assessment of Africa-based Child Eye Health Tertiary Facilities (CEHTF; paediatric surgical facilities designed to cover a population of approximately 10 million¹⁸), carried out in 2008,¹⁹ found that only 33% of CEHTF had active case finding programmes, the number and the quality of these programmes has since expanded. New or expanded programmes have been reported in Nigeria, Ethiopia, Zambia, Tanzania, Malawi, and Madagascar, to name but a few countries. Although there has been limited documentation, it is likely that the expanded case finding programmes have increased the number of children receiving surgical services for cataract.

Surgical management

Across the continent, the actual surgical management of cataract in children has become more specialized, if only because of the increasing number of ophthalmologists who have received training in paediatric ophthalmology. Some fellowship training has been combined with the adoption of a more team based approach to services for children; anaesthesia services have generally improved and low vision care has been included. The availability of less-expensive foldable IOLs, as well as better follow up, has also led to a greater willingness of ophthalmologists to implant IOLs. Research carried out in a number of countries has shown that, although many children still present late for surgery, that outcomes are much improved from previous experiences.^{20–22} The most recent study, from Tanzania, indicated that 62% of eyes had a visual acuity of 6/18 or better at final follow up.²² Multivariate analysis showed that poor clinical outcome remained associated with pre-operative blindness. Interestingly, a recent survey of schools for the blind in Malawi, Kenya, Uganda, and Tanzania showed that among the 196 children with cataract enrolled at these schools only 32 (16%) had not had surgery²³; a previous survey (1994) at schools for the blind showed that only almost no child with cataract had surgery.²⁴ Not only has access to surgery expanded in these countries but the quality of surgery has also been good, judging by the fact that only 17 (10.4%) of the 164 operated children had vision loss due to surgical complications.²³ Similarly, surgery for traumatic cataract in children has also been shown to have good results; in Kenya 1 month after surgery 65% of eyes had a vision of 6/18 or better.²⁵

Postoperative care

Reports of outcomes in the literature from Senegal²⁰ and Kenya²¹ have indicated the problem of post operative follow up. In Senegal 30% and in Kenya 23% of children did not

return for follow up at 3 months. Research in Tanzania focusing on follow up (even when transport costs were provided) indicated a number of factors associated with poor follow up: parental lack of awareness of its importance, long distances, female gender of patient, and poor pre-operative vision.²⁶ This research led to the adoption of measures to improve follow up, including better counseling of parents by a dedicated coordinator, adoption of a tracking system and cell phone follow up to parents who failed to return. After adoption of the new strategies, 10 week follow up (at which time spectacles and low vision devices are ideally provided) increased from 43% to 83% and gender inequity in 2 week follow up was eliminated.²⁷ These strategies are increasingly being adopted throughout Africa and it is likely that post-operative follow up will continue to improve.

The availability of donated or low cost (but attractive) frames for children has increased the number of children being fitted with and using spectacles. High quality low vision devices, now more easily sourced than previously, has meant that most CEHTF now can provide needed optical and low vision services for children after cataract surgery.

Linking with appropriate educational facilities

While improvements in case finding, surgery, and post operative care have been significant, there has been more limited success in ensuring that children are placed in appropriate educational settings and receive educational services that match their needs. The schools for the blind surveys of Kenya, Uganda, Tanzania, and Malawi revealed a high proportion of inappropriate enrollment, many of the children being those who have had cataract surgery.²⁸ It was also learned, from prospectively following children after surgery for congenital or developmental cataract, that far too many children were being placed in educational settings ill-prepared to provide necessary educational opportunities.²⁹ The paucity of information from other settings in Africa make it difficult to know if inappropriate placement is a focal problem or a wide spread problem. In the settings where research has been undertaken, the reasons for inappropriate enrollment are many. Many countries do not have enrollment criteria or guidelines for schools for the blind and many children enrolled have never been examined by an ophthalmologist or low vision technician. Government sponsored schools generally come under the Ministry of Education and there is often little communication or coordination with the Ministry of Health. For some schools there are financial or other incentives to enroll as many children as possible. While eye care professionals may feel that their responsibility ends with the clinical care, if African children with cataract are going to achieve their visual and social potential, efforts will be required by eye care providers to coordinate more closely with educational services.

Summary

Much of the change in our understanding of childhood cataract as well as improvements in service delivery is the result of investment by non-governmental organizations, academic centres, and others in research, training, and programme development. The geographic distribution of research, training, and programme development has been

uneven in Africa with central and west Africa being under-represented. Generation of evidence and careful planning for service delivery reduces the possibility of duplication of services or wastage of funds on interventions that are not effective.³⁰ In Africa, and globally, the adoption of a comprehensive approach to childhood cataract (from case detection through education and rehabilitation) is likely to expand, benefiting children and their families.

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