# CHILDHOOD CATARACT IN AFRICA


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# PREFACE FROM THE EDITORS

Cataract is a leading cause of blindness of children in Africa. Managing this condition so that children receive high quality surgery early and have appropriate follow up for spectacle correction and low vision assessment will ensure that children with cataract in Africa have the best possible quality of life.

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# BACKGROUND

## Prevalence of childhood cataract in Africa

Childhood blindness has been little researched in Africa, for understandable reasons. A rare condition, blindness in children would require large population samples to assess properly. In addition, the number of specialized paediatric ophthalmologists working in Africa has been quite small, limiting the local capacity for research in this area. Available evidence of the magnitude of childhood blindness has generally been generated through surveys at schools for the blind, with the notable exception of a large population based survey carried out in the Lower Shire Valley of Malawi in 1983. However, the Lower Shire Valley was selected for survey primarily because of a known high prevalence of vitamin A deficiency and measles- related blindness rather than because it represented the situation in other parts of Africa. The schools for the blind surveys were carried out in the 1980s and 1990s by and large, reflect the situation of the previous generation. In many of these surveys corneal disease secondary to vitamin A deficiency and measles were the most common causes of blindness.

More recent research has suggested a significant shift in the causes of blindness in children. Vitamin A deficiency and measles have become less common in most countries, probably because of successful drives to increase coverage of children with vitamin A supplementation and measles immunization. Congenital and developmental cataract are assuming a relatively more important place than corneal conditions due to vitamin A deficiency and measles as causes of childhood blindness in Africa.

Generating estimates of the number of children blind due to cataract is limited by many factors, including the lack of population-based estimates, the likelihood that children with cataract will have higher mortality compared to children without cataract, and poor information systems to report children receiving surgery. From the existing literature, it is estimated that, per million population (whole population) there are likely to be a backlog of 100 children with blinding cataract. In areas with strong programmes aimed at finding children and providing them with surgical services, this backlog is likely to be considerably less. On an annual basis, it is estimated that there are about 20 children with incident blinding cataract (congenital or developmental). The backlog or incident number of children with traumatic cataract has not been estimated in Africa, but is likely to be less than congenital or developmental cataract.

# Etiology of congenital and developmental cataract

Cataract in children in sub-Saharan Africa is conveniently divided into congenital, developmental, and traumatic. Congenital cataract, apparent at birth or within the first few months, may be due to a wide range of causes, including infections or teratogens (drugs and other chemical that interfere with normal development) in the mother, metabolic diseases in the child, or other genetic abnormalities. Rubella is anticipated to account for 15-20% of congenital cataract in Africa. The visual pathways (connections in the brain) necessary for good vision do not develop until after a baby is born. This process is partly controlled by genes, and partly by external visual stimuli. If the baby is unable to see, insufficient connections will develop. Therefore surgery must be carried out as soon as possible or a child may not completely restore sight.

In fact, the majority of this development takes place in the first three months of life after delivery. This is known as the "critical period" and loss of vision during this critical period is likely to be permanent, because, even if the problem is treated later, the nerve cells will no longer be able to develop the necessary connections, and perfect vision can never be achieved. Furthermore, once the cataract is removed, appropriate refractive correction (intraocular lenses and spectacles) must be provided in order to ensure a sharp image on the retina; otherwise the visual pathways will still not develop properly.

Developmental cataract is defined as a cataract developing in an eye of a child that has had normal vision since birth for a period of two years or more. As these children have developed some normal pathways for vision, surgery (even after a delay of a year or more) is more likely to have a good outcome than in congenital cataract, particularly if the cataract does not develop until after the child is 5 years of age. However, when vision is lost during the first five years of life, then established connections may also be lost; new connections can only be established during the first five years of life. Thus developmental cataract in young children also requires timely treatment.

Traumatic cataract is rarely listed as a cause of blindness as most of these children have trauma to only one eye. Nevertheless, removal of traumatic cataract is common, as these children already require surgery for the co-existing intraocular injury.

# Amblyopia

If the eye fails to develop connections to the brain, or, if connections to the brain are lost, this leads to amblyopia. Amblyopia is not a disorder of the eye; it is a form of brain damage induced by a visual deficit. When an eye is amblyopic, cells in the brain that usually respond to input from that eye are greatly reduced. Amblyopia may be caused by:

- Deprivation (blurred image or no image, such as occurs with cataract)
- Anisometropia (different refractive errors in the two eyes)
- Strabismus (misalignment of the eyes, also known as squint)

Untreated congenital cataract causes deprivation amblyopia. Even if the cataract is removed, aphakia in one eye combined with a normal lens (or pseudophakia) in the fellow eye may cause anisometropic amblyopia. Congenital cataract is frequently associated with squint, so strabismic amblyopia can occur as well. The eye is most sensitive to amblyopia during the first few months of life; even a week or less of unilateral deprivation during this time can lead to amblyopia and loss of binocular interactions. Older children are at less risk. Temporary loss of vision after the age of six or seven is very unlikely to lead to amblyopia. Amblyopia may be treated by patching the better eye to force the brain to use the amblyopic eye. This may work well in young children, provided the eye has the potential to regain good vision, but becomes less effective as the child gets older.

The ability to fix the gaze on an object of interest must also be learned. Steady maintained fixation usually develops by the age of three to six months. If there is no clear image on either retina during this time, the eyes will be unable to fix on an object, and the child will develop nystagmus (involuntary jerky or rhythmic movement of the eyes). If vision is restored before the age of two, some degree of central fixation may be regained. After the age of four, nystagmus is usually permanent.

The most common cause of amblyopia is strabismus and in these cases the amblyopia is usually unilateral. The challenge of cataracts occurring in early childhood is that they can cause bilateral amblyopia. In young children with bilateral cataracts, amblyopia is more common in the second eye to have surgery.

The evidence from Africa suggests that although childhood cataract is a potentially curable condition, half of the operated eyes end up with a vision of less than 6/60; much of this is due to amblyopia. Consequently, the challenge of congenital and developmental cataract in Africa is not simply a matter of addressing the issue of surgical quality; equally important, and perhaps more challenging, is providing the surgery to the children before it is too late and providing the follow up care with refractive correction and low vision services after surgery.

# PLANNING FOR CHILDHOOD CATARACT IN AFRICA

There are no specific recommendations for managing childhood cataract in Africa, however, at a WHO meeting in 1999 recommendations were developed for addressing the broader problems of childhood blindness. From this meeting the concept of a “Child Eye Health Tertiary Facility” (CEHTF) was developed and described. It was recommended that there be one CEHTF per 10 million population. In response to this initiative WHO and Lions SightFirst identified 5 government tertiary eye care centres in Africa, each to have an ophthalmologist to receive training in paediatric ophthalmology. Concurrent with this initiative other CEHTF have been developed in Africa, all generally focusing on good quality surgical management (with high quality paediatric anaesthesia). Few CEHTF have adequate support services (refractive services, low vision services, counseling, etc.).


Childhood blindness is one of the priorities of VISION 2020; a blind child may have up to 50 years with disability having a significant impact upon his or her quality of life, the family, the community, and the nation as a whole. While many African countries have included childhood blindness in national five year VISION 2020 plans, by and large, childhood blindness has not been included in "district” (population 1-2 million) VISION 2020 implementation plans. A failure to include plans for dealing with childhood blindness into district implementation plans has meant that most aspects of national VISION 2020 plans for childhood blindness have been implemented in only a few settings.

# Current evidence for good management of childhood cataract in Africa

Research carried out eastern Africa has shown that few children have access to an CEHTF, they often come quite late, most do not return for necessary follow up, and many do not end up with proper educational placement that would maximize their visual potential.

Research from Tanzania has shown that the average delay in presentation is three years, with differences noted for children with congenital cataract (just over 2 years) and developmental cataract (three and one half years). "Long delay" was defined as more than 12 months between the time of recognition in the community and surgery. Children living more than 2 hours by public transport from the hospital were two times more likely to have a long delay than children living closer to the hospital. Children with congenital cataract were 2.67 times more likely to be brought in early compared to children with developmental cataract. No gender difference was noted for developmental cataract; however, girls with congenital cataract had an average delay of 30.5 months compared to boys, who had a delay of 20.2 months. Other factors predicting long delay included low socio-educational status of the mother (however, no association with the father's socio-educational status) and being a first-born child (congenital cataract only). All of these factors indicate that socio-cultural factors, which may be amenable to change if addressed properly, are primarily responsible for the low number of children presenting for surgery.

Unpublished data from a survey of health workers in Tanzania interested in prevention of blindness showed that over half felt that a child with cataract should not be brought for surgery until the child is older and the cataract more mature. Thus, the messages that health workers are likely to give parents of children may also delay their presentation.

Interpreting reports of the outcome of surgery on children with cataract is generally problematic because of the poor follow up at tertiary hospitals. Research addressing follow up has indicated that less than half of children who receive surgery for cataract return for follow up and spectacles and low vision assessment and devices. Similar to the problem noted with delay in presentation, poor follow up is generally due to socio-cultural factors such as gender (girls being less likely to be brought back), distance from the hospital, and lengthy delay in initial presentation.

Finally, there is strong evidence of inappropriate school placement of children following surgery. Pilot studies in Tanzania found that, while most children had improved vision following surgery, many were placed in schools for the blind after surgery where they were taught using Braille rather than using print.

This research has led to a better understanding of the possible interventions for children with cataract and to improvements in all aspects of case finding and referral, surgical intervention, follow up, spectacle and low vision correction, and educational placement. Planning for the management of childhood cataract should take the “whole family approach” (including the family in all aspects of care); it should also take a holistic approach to service delivery, including identification and referral, treatment, and follow-up of the affected child.

# "Experts" meeting on childhood cataract

A meeting of experts from a wide range of disciplines (paediatric ophthalmologists, epidemiologists, medical anthropologists, low vision specialists, optometrists, educationalists, programme managers) was held at the Kilimanjaro Centre for Community Ophthalmology (KCCO) in Moshi, Tanzania in May 2007. The meeting, supported by Dark & Light Blind Care, reviewed the existing evidence base in Africa, prepared recommendations on various aspects of management, and drafted the outline for this manual. A copy of the recommendations and the list of participants are given in Appendix I.

# Childhood cataract in national VISION 2020 plans

National VISION 2020 plans should make reference to addressing childhood cataract through both a “whole family” and a “holistic” approach. At the national planning level the following steps are needed.

1. Existing CEHTF should be identified. The catchment area (approximately 10 million people) for each facility should be clearly demarcated. This is necessary to prevent duplication in some areas and lack of service in others.
2. Review the capacity for providing services (identification and referral, surgery, refractive services, and low vision services) at each facility and make plans to address the shortcomings.
3. If CEHTF facilities are unavailable or insufficient for the population, a long-term plan should be developed for establishing and supporting a facility.
4. Training opportunities for all team members, both within the country and outside of the country, should be identified.
5. Basic strategies for identification and follow up of children with cataract should be outlined.
6. A system to monitor the use of CEHTF by children with cataract (by sex and by district of residence) should be established.

Remember that it is unrealistic to expect each "district” VISION 2020 planning area to have its own paediatric ophthalmology tertiary facility; however, each “district” should have a system to find and refer children to a CEHTF.

It is recommended that a small task force, comprising the CEHTF ophthalmologist(s), the childhood blindness and low vision coordinator(s), someone from the fields of low vision and education as well as interested NGOs/donors be constituted to advise the national VISION 2020 or Prevention of Blindness Committee.

# Determine the magnitude of childhood cataract in each country and “district”

The prevalence of blindness in children roughly corresponds to under-five mortality rates and can be used to calculate an estimate of childhood blindness at the national level. The calculation includes consideration of [a] the country population (in millions), [b] the number of children <16 years, and [c] the under-five mortality rate. Information on causes of childhood blindness from schools for the blind, if recent in nature, may help to map the magnitude and causes of blindness in children at the national level. Proportionately, blindness due to cataract will be higher in African countries with good immunization and vitamin A supplementation coverage, and lower in countries with lower coverage.

In either case, the “best guess” estimate is as follows:

100 children blind due to cataract per 1 million population (backlog)
20 children blind due to cataract per 1 million population per year (incident)

Thus, as a first step, census data can be used to calculate the estimated number of children blind due to cataract. This number, representing the backlog of cases, will change as programmes to improve access to surgery are implemented. This figure should be calculated for each VISION 2020 district in the country. As an example, consider Tanzania. VISION 2020 “districts” there are the administrative “Regions” with populations of around 1-2 million. According to estimated population figures, it is possible to calculate the backlog of childhood cataract for the VISION 2020 districts in the southern zone of the country as follows:

* Estimated number of children with cataract

**Estimated number of children developing cataract each year

| VISION 2020 "Districts" | Estimated Population | Backlog* | Incidence** |
|---|---|---|---|
| Mbeya Region | 2,400,000 | 240 | 48 |
| Rukwa Region | 1,322,000 | 132 | 26 |
| Kigoma Region | 1,890,000 | 189 | 38 |
| Mtwara Region | 1,300,000 | 130 | 26 |

# Setting targets and monitoring

The figures above are calculated for the purpose of planning. This would provide targets for members of the VISION 2020 implementation team and the tertiary facility for the number of children that they should aim to find, refer, and (in the case of the tertiary facility) provide surgery for. Planning at the district level should include implementation of systems to monitor the success of activities to find and refer children with cataract.

Targets at the district level should be set and monitored for the following indicators:

1. The number of blind children identified
2. The number of children with cataract identified
3. The number that actually get cataract surgery
4. The numbers that are actually visually rehabilitated (outcome)
5. The numbers that come for follow-up two years after surgery

Each CEHTF should collect and compile information (including age, sex, and “district” of residence) for planning and monitoring purposes. This information should be used to calculate a "Childhood Cataract Surgical Rate” (CCSR) for each VISION 2020 “district” in the country. The CCSR is the number of children (rather than “eyes") with congenital or developmental cataract who have had surgery in a given year divided by the total population of the “district”.

# STRATEGIES TO ADDRESS CHILDHOOD CATARACT

A number of activities will be needed in order to achieve the targets set and to monitor whether they are reached. A section of this manual is devoted to describing different approaches that have been shown to be successful.

## Team approach to providing a service

Achieving the goals of VISION 2020 for childhood cataract requires that a team approach be adopted. Multidisciplinary skills are needed in order to ensure that practical and proper planning is undertaken, that mechanisms for identification and referral of children are designed and implemented, that children and their parents are properly counseled, that their surgery is of high quality, that mechanisms for follow up are established and routinely implemented. It is crucial to ensure that children receive refractive correction and low vision assessment and service, and finally, that they collaborate with the education system for the most appropriate educational environment and follow up.

Generally, a CEHTF lead paediatric ophthalmologist will lead efforts for the clinical care of these children while a “Childhood Blindness and Low Vision Coordinator” is best placed to lead the efforts for coordinating all non-clinical care and training. The list of team members is given on the following page.

| Position | Essential | Useful | Ideal |
|---|---|---|---|
| Paediatric Ophthalmologist | 1 | 2 | 2 |
| Childhood Blindness and Low Vision Coordinator | 1 | 1 | 1 |
| Anaesthetist (Paediatric Competent) | 1 | 1 | 1 |
| Optometrist* | 2 | 3 | 4 |
| Theater Nurse | 1 | 2 | 2 |
| Dedicated Clinic Nurse | 0 | 2 | 2 |
| Counselor** | 1 | 1 | 2 |
| Records Clerk | 0 | 1 | 1 |
| Paediatrician (Part-Time) | 1 | 1 | 2 |

* alternatives include: refractionist, low vision, VA assessor

**alternative: childhood blindness coordinator

# Detection and referral of children with cataract

The outcome of cataract surgery in young children is very much dependent on the cataract being identified early, and the prompt referral for treatment. In Africa many babies and young children have contact with health workers at different points during infancy and childhood, all of which provide opportunities for infants with cataract to be identified. The evidence, however, is that that opportunity is either not taken or, when taken, does not lead to proper referral for surgery.

Primary health workers do not have the skills to differentiate a “white pupil” suggesting that the primary approach would be for them to simply refer any child with a “white pupil” as an emergency to a better-trained eye health professional. The health care worker needs to be able to counsel the parents that the condition could be potentially life threatening (e.g. retinoblastoma) and more qualified assessment is needed.

# Clearing the backlog of existing cataract blind children

In most African countries there is a large backlog of congenital or developmental cataract in the community. Strategies to clear this backlog should be considered when there are facilities to which these children can be sent for surgery. Clearing the backlog will identify many children who, after surgery, will not have a good outcome but, who, in most cases, the outcome (with proper refraction and low vision services) will be better than blindness. Clearing the backlog will serve a number of other purposes:

- It will generate awareness of the problem among professional and non-professional groups
- It will set the stage for putting in place plans for addressing incident cases
- It will be a learning tool for the team to better address the barriers to the uptake of surgery

Strategies to clear the backlog have not been tested adequately but evidence suggests that a number of different approaches can be taken:

## Radio messages

There is good evidence that radio messages addressing the problem of childhood cataract will lead to more children having surgery. The messages need to be clear and concise: [a] a "white spot" in the middle of the eye should be viewed as an emergency, [b] if treatment is needed, this will be provided free, [c] the location that the child should be taken for assessment.

## Using “Key Informants” to identify children in the community

There is evidence from a couple of countries in Africa that using “key informants” (village people who create lists of children who are “blind” and bring them to a central location for examination by a clinician) can be effective in identifying many children with cataract. Evidence suggests that one key informant could cover a total population of 1,000 to 2,000. In that population a key informant may find no blind or severely visually disabled child.

Using community-based key informants in Africa may require some form of honorarium paid; using government health workers as key informants (KI) is likely to be more costly. In either case, training is very basic and does not aim to enable KI to test vision—simply to know how to collect names of children who are “blind” or have severe visual impairment.

Monitoring the activities of key informants (using cell phones) can enhance their output. Thus, one community mobilizer (salaried person) can monitor KI for one district in a phased manner. The community mobilizer can be an itinerant teacher or ophthalmic assistant. In either case, some form of transport is needed to reach the communities. Evidence also suggests that having a clinician come at a defined time to a defined location to examine all of the children identified is helpful.

Once a child has been identified, the programme may need to provide the funds for transport of the child (and parents) to the hospital or inform the parents that travel costs will be reimbursed.

## Identifying children with cataract at schools for the blind

In many countries of Africa schools for the blind admit children without an ophthalmologic assessment; consequently it is not unusual to find children with cataract at schools for the blind.

All schools for the blind and annexes should have a visit by a qualified eye care professional on an annual basis to detect children with cataract, posterior capsular opacification and uncorrected aphakia and pseudophakia. The children who can be improved either by surgery, refraction or low vision aids should be provided these services.

All schools for the blind should have admission criteria for children with blindness and low vision. In particular, these admission criteria should include assessment by an ophthalmologist and refractionist prior to admission. In some countries where criteria exist but are not implemented, it will be important to set up a mechanism to work with the schools to adopt the criteria. Low vision testing should be mandatory for all children with any functional vision.

# New (incident) childhood cataract cases

Addressing the backlog does not negate the need to put into place strategies to identify new cases of cataract in the community. Strategies tested and shown to be effective in Africa are few in number; they are not exclusionary and it is likely that multiple approaches will be needed. The use of “key informants”, as discussed above should not be considered adequate for routine recognition of incident cases of cataract. As noted in the section on addressing the backlog use of radio is an important approach. Other methods include:

## Community to hospital “bridging strategies”

For areas that have strategies in place to bridge communities and hospital with general eye care services, these approaches may be effective in identifying children in need of surgery. This may require re-tooling of the approaches (which primarily focus on the needs of adults) to address needs of children. Community leaders (which may include village leaders, religious leaders, or women’s groups) may be effective in getting children for screening.

## Itinerant teachers

In some settings in Africa itinerant teachers, who are in the practice of visiting special care children at their schools or at home, may be in a position to identify children to be assessed for cataract. To be successful, these itinerant teachers need to have a good relationship with community leaders to ensure that any children with new incident vision loss are seen by the itinerant teacher.

## Primary health care workers


Health workers responsible for immunization may be effective in identifying and referring congenital cataract (although generally not developmental cataract) cases. Using primary health workers requires some re-training and the development of posters and brochures. A copy of a brochure is given in Appendix II. Although untested, it might also be possible to get traditional birth attendants trained; it should be recognized however, that due to the rarity of congenital cataract it is possible that a traditional birth attendant may never identify a single case. This will have implications for the cost of training. Including recognition and referral of a "white pupil" in general health care curricula may be a long-term solution.

# Health communication materials to enhance case detection of childhood cataract

Whether for identifying backlog of cases in the community, or incident cases there is a need for using different communication tools.

- Posters and leaflets (preferably colored) with large photographs of a child with cataract and can be printed and displayed at schools, nurseries, health centers, shops and places of worship, bus stops and tea shops are likely to be useful
- Use of radios: Health messages and programs about childhood cataracts on the radio should be used. The use of jingles may also be helpful in getting messages considered in a routine fashion. The experience of experts who have worked on the immunization and HIV programs can be utilized.
- All health communication materials should include a contact telephone number (landline and/or mobile) of the hospital and detailed address and P.O. Box of the hospital so that people know where to go

The health communication messages should highlight that:

- Cataract can happen in a newborn and in a young child
- Surgery is the only way to treat childhood cataract
- The surgery is safe and vision can be restored
- The sooner the surgery is done for cataract, the better it is
- Surgery can be done in children as young as one month of age and it is safe
- You should not wait for the cataract to "get mature"
- White pupil in children should be treated as an emergency and referral to eye doctor
- Delay in surgery can cause irreversible blindness

Guidelines for referral for everyone (teachers, parents, relatives, key informants, immunization workers, traditional birth attendants, midwives, nurses, pharmacists, etc.) need to be clear and concise:

- All children with white spot in the eye should be referred to a pediatric eye care centre/ regional hospitals
- All children with any obvious eye abnormality (small eye, white spots, squint) need to be referred to pediatric eye centre/regional hospitals
- All children where the mother thinks they have some problem with the eyes/vision should be referred to pediatric eye centers / regional hospitals

(A child who has been successfully rehabilitated can be used for radio/ TV/posters.)

Guidelines for referral for physicians and eye care professionals (general practitioners, pediatricians, optometrists, ophthalmic assistants, cataract surgeons, general ophthalmologists):

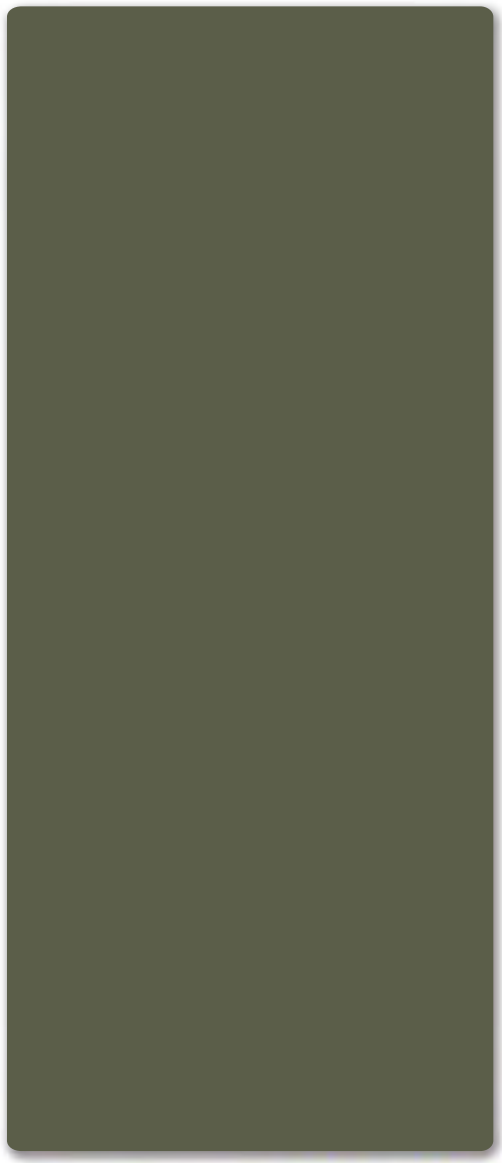
- All children with low vision and cataracts need a detailed eye examination, with dilatation of pupil, retinoscopy and fundoscopy
- It is important to examine the siblings of children with cataract
- Parents should be reassured that cataract blindness in treatable and the surgery is safe
- Any child with a "white pupil" should be referred to children's eye centre / regional hospital as an emergency

In some situations primary level health workers may not be aware of accepted guidelines, in particular, the need to refer children to a regional eye center or child eye centre. Primary health workers are generally unaware of "low vision care"; including appropriate information on congenital and developmental cataract (and all of its components) and strengthening the existing curricula of training programmes is needed.

# Getting children to the hospital for surgery

Identification of children, whether through itinerant teachers, health workers, or through other mechanisms, needs to also include consideration of how identified children will actually get to the hospital for surgery. There is ample evidence that simply telling a parent to take a child to hospital for assessment and possibly, surgery, is ineffective. More pro-active approaches are likely to be needed. Possible approaches used in a number of settings in Africa include:

- If using key informants in a "burst" approach to find children in need of intervention, it has been shown that it is necessary to have someone with sufficient clinical skills (although generally, not an ophthalmologist) make a visit to a site to examine children identified by the key informants. One of the tasks to be carried out in this setting is to identify those who can be benefit from an intervention (surgery, low vision) and/or require further assessment.
- Since transportation has been shown to be a significant barrier to accessing surgical services for children in Africa, providing the cost of transport for the family to reach the surgical facility is likely to be necessary. If possible, when children are detected by a visiting a team it is best to offer to take the child and parent(s) to the hospital that day.
- At the time of diagnosis in the field it is helpful to get the cell phone number of the parents of the identified child. Sometimes, the phone number will be of a neighbor or a nearby shopkeeper. This information is then given to the manager of the district VISION 2020 programme who will be responsible for calling the parents of all identified children to make sure that they present to the eye hospital. In many cases it may require several follow up calls; experience shows that persistent effort from the hospital can ensure higher uptake.



# Within institution referral

It is recognized that there are opportunities for referral and education within institutions that have both a paediatric ophthalmology tertiary facility as well as more general paediatric or maternal centres. To date, these natural linkages have not been exploited well. A possible approach would be to encourage maternal, pediatric, dermatology and general ophthalmology clinics to refer all children suspected of having cataract and/or poor vision to the pediatric eye clinic.

# Counseling

Counseling is a critical component of service delivery for an eye care programme for children. Generally, prior to presentation at the surgical facility, counseling is fairly limited, primarily focused on the steps needed to help parents to reach the surgical facility.

Good quality counseling must be provided at the time of admission to hospital, during the time of surgical treatment, and at the time of discharge. Counseling is also necessary at each follow up period. The counselor generally assumes the role of the “patient advocate”; good quality counseling leads to better compliance to medical and surgical treatment, follow up care, and long-term management. It must be remembered that overloading the parents with information all at one time is not helpful. Parents need to receive information, often repeated, at multiple occasions and in different formats. An example brochure for parents is given in Appendix III. Thus, it is best to break up the messages to be given [a] at recognition and admission, [b] prior to surgery, [c] just after surgery, and [d] at discharge. In addition, there are messages to be given at follow up.

Counseling has been shown to improve follow up and use of refractive and low vision services as well as better understanding by parents of their role and responsibilities and overall satisfaction with the service.

## Counseling at detection

Parents should receive some counseling at the site of detection (by key informant, health worker, eye care workers, etc.). Counseling should focus on the treat-ability of the condition, the urgency of treatment and the availability of free or subsidized services.

## Counseling on admission

The most important counseling occurs at the time the parents and child present to the hospital. Counseling focuses on pre-operative work-up, surgery, anesthesia, use of intra-ocular lenses, and all components of post-operative management. The need for glasses after surgery and long-term follow-up are emphasized. At the time of recognition and admission, counseling should focus on the following messages and issues:

- Management of cataract in children requires a holistic approach rather than just a surgical approach
- Childhood cataract is not like adult cataract and needs a long term process of activities and interventions before surgery, during surgery, and after surgery
- Childhood cataract is a rare condition, however it can run in families and other family members should be examined
- The only treatment for childhood cataract is surgery; surgery should be carried out as soon as possible so that the child can start "learning" how to see

## Counseling prior to surgery

Prior to surgery, additional counseling should focus on the following messages and issues:

- In most cases surgery will not give the child "perfect vision" because, in many cases, the eye had not "learned" how to see. Improvement in vision can be slow, and may take several months, or even years.
- The operation is only the first step in a long process of rehabilitation. Clinic visits and new spectacles will be required frequently, and occlusion therapy, or additional operations may be required.
- There are risks associated with surgery—primarily in terms of anaesthesia. Thus, consent must be given.
- Many children with cataract have other conditions (associated with cataract) that may require treatment
- After surgery the child will need to stay in hospital for several days or up to 2 weeks (depending on how far away he lives) to allow for close follow up

## Counseling at discharge

After surgery and also at the time of discharge counseling should focus on:

- The parent will have to administer eye drops for a period of time after leaving the hospital
- Children who have had cataract surgery need long-term follow up (throughout childhood) to make sure that they achieve the best possible vision
- In many cases there will be a need for the child to wear spectacles and to use low vision devices. It is up to the parents to encourage children to wear the spectacles. If spectacles are provided free of charge, parents should be informed. It should be stated that any contribution by the parents for transportation, spectacles or other services would be helpful.
- Only after refraction and low vision assessment will it be possible to work with the parents to decide on the most appropriate educational environment for their child

- Parents need to be given specific instructions on when to return to the hospital. If transport expenses are provided for follow up, they should be informed of this.
- The parents will be contacted by phone if, for some reason, they fail to come for their follow up
- The “Childhood Blindness and Low Vision Coordinator” is their contact person and the parents should feel free to contact that person at any time

## Counseling at follow up

At the time of follow up counseling should focus on:

- Appreciation to the parents for bringing the child back for follow up should be clearly stated
- What is expected for follow up (examination by the ophthalmologist, vision testing, measurements for spectacles (if needed), and low vision assessment
- Spectacles will need to be changed as the child grows
- The appropriate educational placement needs to be outlined clearly. If possible, someone from an educational institution should also be present.
- If other rehabilitation needs are identified, the location of the rehabilitation centre should be provided
- When follow up is possible external to the surgical facility, the location of the facility, name and phone number of the contact person should be provided

## How to counsel

- Counseling should be done in the parents’ own language in a comfortable room with some privacy
- If possible, both parents should be involved in the decision for surgery and the counseling. Involving a family elder or other important family member may also be helpful, as women generally do not have decision-making capabilities in most African households.
- The parents must be given ample opportunity and time to ask questions and they should be dealt with patiently

- If the child is more than 8 years old, the child should be part of the counseling
- The counselor should always be polite and have empathy. The parents should be treated with respect, whatever social class or tribe they belong to.

Background leaflets on childhood cataract (in the local language) are extremely helpful. All parents should be provided a letter for follow up (showing the date of follow up).

The amount of time needed for counseling depends on the educational level of parents. Some general guidelines are as follows:

- At recognition/admission: (includes interview to get background information on the child and family): 30 minutes
- After admittance (and before surgery, on the ward): 15-30 minutes
- After surgery, before discharge: 10-15 minutes

Avoid group counseling; each child and family is unique. Each family also needs time to ask questions. While counseling focuses on the needs of the family and child, at the time of the 3 month follow-up it will be important to prepare the parents with information to give to teachers about the visual needs of the child.

# Developing a programmatic approach to recognition and referral of children with cataract

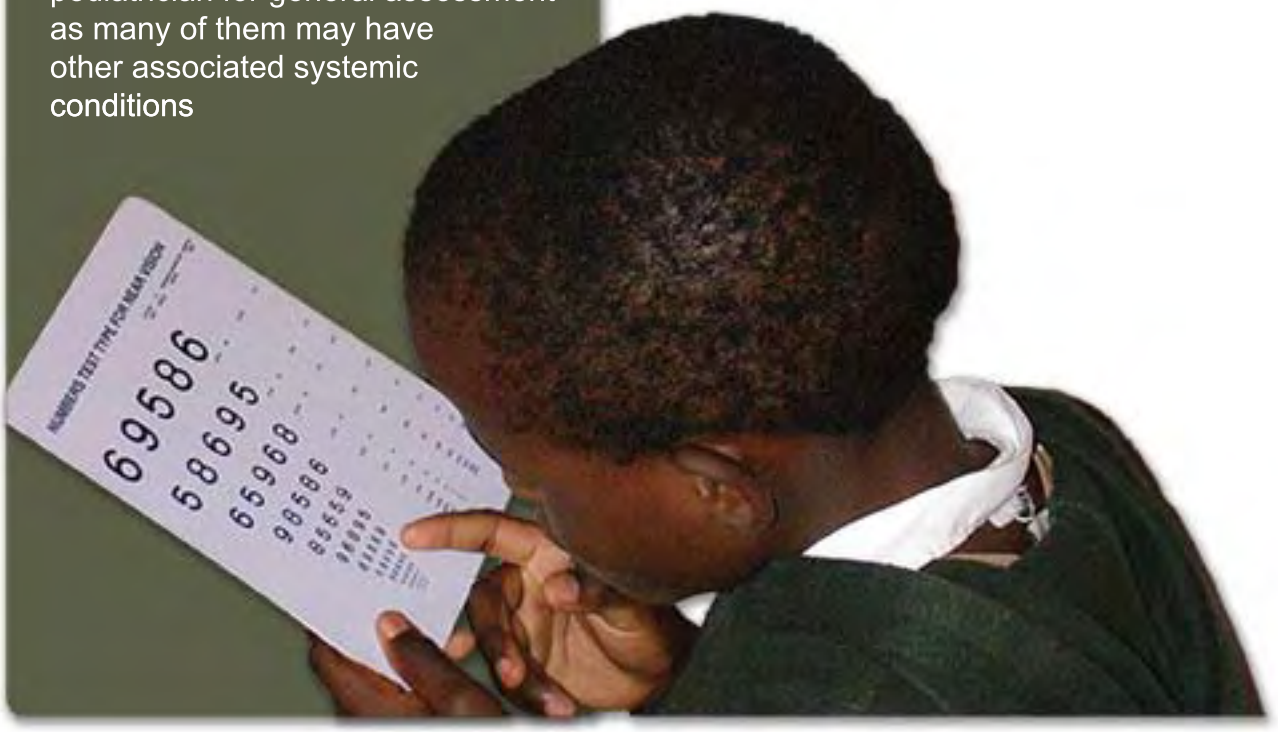
All of the strategies listed above lend themselves to the adoption of a programmatic approach to recognition and referral of children. By necessity, the programme would need to be based at the paediatric ophthalmology tertiary facility covering a population of 10 million people. Besides developing and implementing the strategies

described previously, the programme should also do the following:

- Develop a database of all children in the catchment population who are identified as severely visually impaired or blind (including children with cataract). While the approach will vary from country to country, according to the health system and the context, it should entail use of a simple short form (including name, age, detailed address of the child along with both parents' names, and a telephone number). This form can be used by all engaged in "case finding". Whenever a blind child or a child with cataract is identified, he/she is registered with a copy kept by the case finder and a copy sent to the eye center.
- Anyone engaged in "case finding" should be trained in use of reporting forms as well as being provided with a referral form/letter giving detailed information about the surgical facility (location, address, contact telephone number (landline and/or mobile), and person responsible). If a policy to reimburse travel is adopted information on its use should be well circulated among the case finders so that people do not delay their hospital visit because of travel costs. Finally, many hospitals have a policy of free or highly subsidized surgery for children; if that policy exists, it should be publicized among the case finders and in the community.
- Paediatric ophthalmology tertiary facilities should take the lead in establishing and maintaining referral linkages with rehabilitation experts and school teachers for identification, services and follow-up of the children with cataracts. While the linkage starts out in terms of referral of children for surgery, it should be effective both ways, enabling children who have had surgery to be placed in the most appropriate educational environment.

A programmatic approach benefits from the adoption of specific guidelines for “best practices”. Specifically, include some of the following:

- All children having best corrected vision less than 6/18 should have a low vision assessment
- All children operated for cataract should undergo refraction and/or low vision assessment before discharge
- All children operated for cataract should have an annual check-up for refraction and low vision assessment
- The ophthalmologist and low vision specialist should write a referral letter detailing the best possible educational environment for the child, including any advice for primary learning medium (print, Braille, other)
- Children with cataract and low vision should have a referral to a pediatrician for general assessment as many of them may have other associated systemic conditions



# PRE-SURGICAL ACTIVITIES AT THE CEHTF

## Investigation of the cause of cataract

At the time of diagnosis of cataract in a child, history taking is extremely important. Babies will normally fix on their mother's face by 6 weeks, and parents are the first to realize that there is a visual problem if this does not happen. Children with very poor vision may not show any response to bright light (most babies would close their eyes when moving from a dark to a brightly lit environment). Family history may be useful when assessing the likelihood of future visual loss due to the cataract in dominantly inherited cases. If a parent has not been operated, and has nystagmus, this would be a relative indication for surgery.

For older children, ask if their vision is bad enough to prevent them from participating in normal activities with other children of their age. Specific questions that should be addressed include:

*Is there a family history of cataract or visual problems during childhood?*
This should include specific questions about three generations on both sides of the family – siblings and cousins, aunts and uncles, and grandparents of the affected child.

*Did the mother have any illnesses during the pregnancy?*
Especially any acute illness associated with fever and rash

*Did the mother take any drugs during the pregnancy?*

*Is the child's general health good?*
This should include specific questions about whether she/he been growing and developing normally and whether the parents have any other concerns about her/his health. More specific questions will be necessary when there is a suspicion of a systemic disorder.

*When did the parents first suspect the child had an eye problem?*

*Has the child had an injury to the eye or had a red (inflamed eye) at any time?*

*Is the child taking any medicines?*

# Clinical examination at the time of diagnosis

## Examination of the family

Wherever possible, it is important to examine the eyes of parents, all siblings and any other close relatives who are available, to see whether they have any degree of cataract. In many families with hereditary cataract, the type and density of the cataract can vary from person to person. Some affected individuals with cataract may not be aware of them. For these reasons the examination should ideally be undertaken after dilating the pupils, at the slit lamp.

## General (paediatric) examination of the child

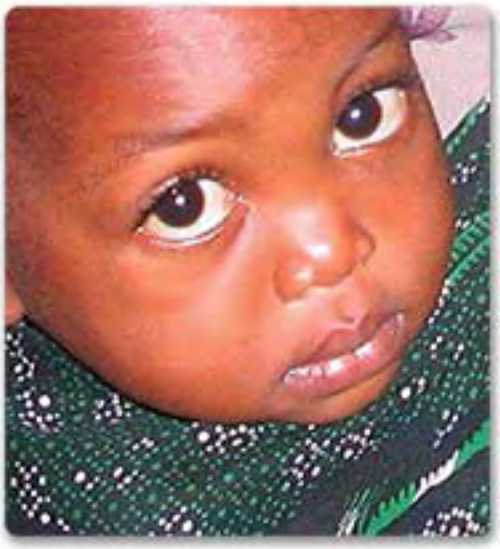
Those children who are suspected of having an underlying systemic disorder – e.g. because they are unwell or have delayed development - should ideally be assessed by a paediatrician who can undertake further investigations, as required. In most settings, this will apply to a minority of children with cataract. All children (even those who have no obvious medical problems) must be assessed for fitness for general anaesthesia by the anaesthetist responsible.

## Special investigations

In general, in an otherwise healthy child with isolated cataract, especially if unilateral, it is unlikely that an underlying cause will be found using special investigations. Equally, a healthy child with a clear family history of hereditary isolated cataract will not need further investigations.

Wherever possible, specific investigations for underlying systemic disorders are best undertaken by the paediatrician / anaesthetist who has assessed the child. This will help to ensure that only relevant investigations are carried out and the results are interpreted in the light of broader clinical findings, for example tests for specific metabolic disorders such as galactosaemia. This will also help to avoid any delays in providing, or uncertainties about appropriate treatment, where necessary.

Prenatal rubella infection is an important cause of congenital cataract in some countries in Africa and some infants may present first to ophthalmic professionals. Children with rubella cataract nearly always have other signs of the disease (e.g. heart disease, deafness, microcephaly). In some settings blood or saliva samples can be used to identify IgM antibodies to rubella, indicating new



infection in infants. These tests can only be done on infants under the age of 12 months - after that a positive test may be due to acquired infection rather than congenital infection.

If trauma is suspected, e.g. an older child with unilateral cataract noticed recently by the parents, but a dense cataract is present which prevents full examination of the posterior segment then imaging using X-Ray, CT scan, or ultra-sound B-scan, as available, will help in identifying foreign bodies in the eye or orbit or a retinal detachment. This would have implications for the surgery required and for visual potential.

# Testing vision in children

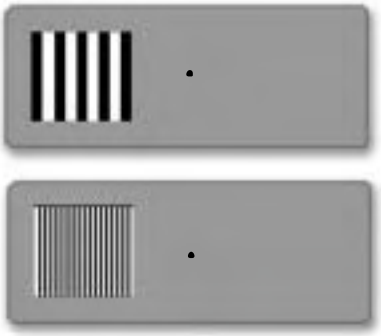
## Testing vision in neonates / infants

Ideally cases of congenital cataract will present to the ophthalmologist soon after birth since this offers the possibility of early surgery, however this is generally not the case in Africa. It is difficult to quantify visual responses in children as young as this. The most important aspect of the examination at this age is observation of the child's visual response (fixing and following) to human and parental faces. This should be performed binocularly and uniocularly in case there is asymmetrical severity of the cataract. If a baby exhibits good fixing and following behavior with partial cataract, surgical intervention may be delayed and repeated visual assessment performed at regular intervals e.g. 3 months. If the baby does not fix and follow (provided that cataract is felt to be the cause of the poor vision), urgent surgery is indicated. Occasionally eye movement abnormalities interfere with fixing and following, and give the appearance of poor vision.

Infants presenting later may have a squint or nystagmus, which indicates that deprivational amblyopia is already developing. It is important to look for asymmetric amblyopia by observing fixation preferences. Cover / uncover tests are difficult to perform in this age group, but it is relatively easy to observe binocular fixation pattern to determine if one eye is always preferred.


LEA Gratings

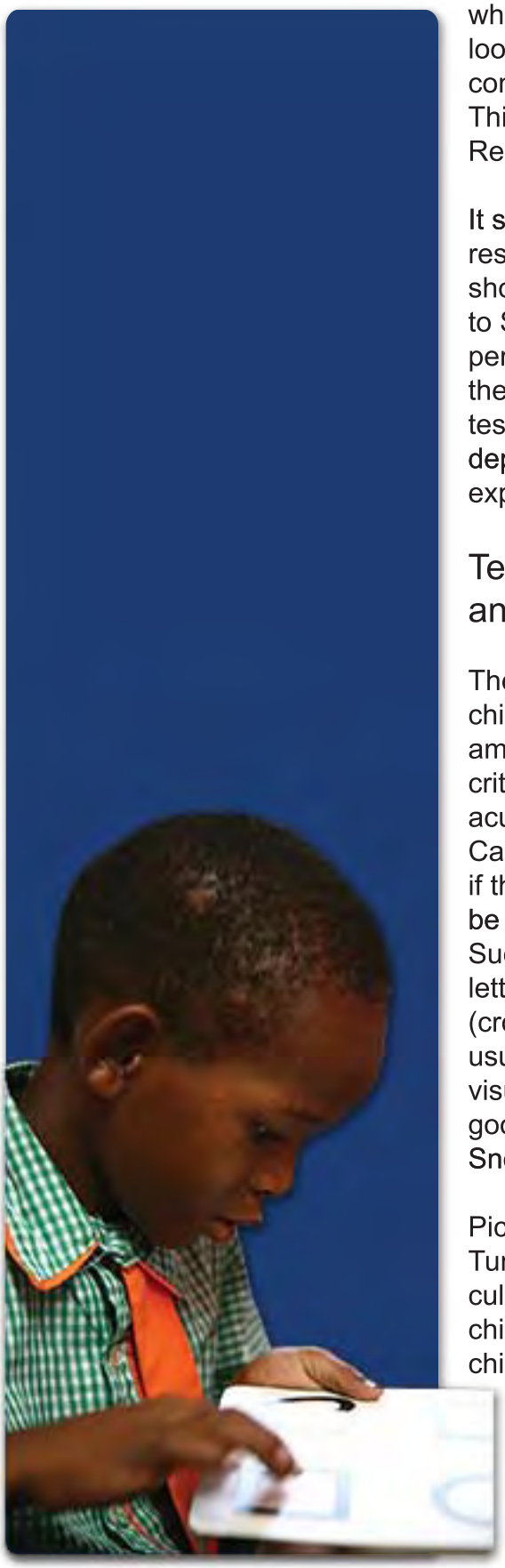
A widely used clinical classification of vision at this age is the CSM classification
- Central: Fixation of visual targets
- Steady: Absence of nystagmus
- Maintained: Follows visual targets that have been fixed and are then moved slowly by the examiner. Maintained fixation also refers to maintenance of fixation during a switch from monocular to binocular fixation (i.e. when the eye is uncovered after a positive cover test, does it maintain fixation, or does it deviate away again as the fellow eye resumes fixation).


Teller Acuity Cards

The CSM notation is a useful way of recording vision in the records but should not be thought of as quantitative; central, steady fixation is compatible with visual acuities ranging from 6/9 to 6/36.

Quantitative measurement of visual acuity at this age (0 to 2 years) requires preferential looking techniques. The Teller Acuity Cards and LEA gratings are 2 examples of a preferential looking test which adapts the principle that when an infant is presented with 2 targets he/she would prefer to fixate on a complex pattern rather than a plain stimulus. Using Teller, the child is presented with a series of large cards each containing two target areas, one plain grey, and one with black and white stripes. The assessor observes the child's eye movements through a small hole in the card and decides which way the child is looking. The size of the stripes is gradually reduced and at a size corresponding to the child's limit of resolution, the black and white stripes will just appear as a grey blur and the fixation preference will be lost. LEA gratings uses 2 paddles, one with the black and


Crowded logMAR Kay Pictures



white stripes and one grey. Another preferential looking test, Cardiff acuity cards, utilizes pictures constructed of black and while lines as the stimulus. This test is useful for children from 1 – 3 years. Response to torchlight should also be tested

It should be noted that these tests measure resolution acuity rather than recognition acuity and should not therefore be assumed to be equivalent to Snellen acuities. These tests often have to be performed at short distances for infants and therefore become very sensitive to small changes in testing distance, reducing their reliability. They also depend on the child's concentration, the tester's expertise and must be interpreted with caution.

## Testing vision in older children (3 years and older)

The decision on whether to operate on older children is usually easier. Although deprivational amblyopia remains an important consideration, the critically sensitive period is over. Matching tests of acuity are preferable, such as the HTOV, Cambridge Crowding Cards or logMAR tests. Even if the child is not familiar with letters, matching may be possible, and easier than recognizing pictures. Such tests are usually available with both single letters (single or uncrowded) and rows of letters (crowded) as targets. Children with amblyopia will usually perform better with single letter targets. A visual acuity of 6/12 with a single letter test is not as good as a visual acuity of 6/12 with a standard Snellen chart.

Picture tests such as the LEA symbols, and the Tumbling E test, have found to be relevant in most cultures and can be used for older but illiterate children. (The gold standard acuity test for older children is the logMAR acuity test.)

Preferential looking cards such as the Cardiff acuity cards can be useful and may be used at greater distances if the child is able to name pictures. Kay's pictures are another acuity test

that depend on the child recognising and naming pictures – if they have not been exposed to books, or their language is delayed, this may be difficult. In addition the pictures may not be culturally relevant.

Quantitative measures of acuity provide a means of following changes in vision over time. Visual acuity results will normally improve with practice and with age. The decision to operate is normally made by assessing functional vision i.e. deciding, in conjunction with the parents, if poor vision limits the child's performance of normal childhood activities.

# Examining the eyes

A careful examination of the whole eye is crucial, not just to assess the cataract but to detect any other ocular abnormalities that may affect management. Systemic abnormalities associated with cataract have been dealt with in a previous section but cataract may accompany other ocular disorders.

| | |
|---|---|
| Cornea | Peters anomaly |
| Vitreous | Persistent hyperplastic primary vitreous |
| Retina | Retinopathy of prematurity |
| | Retinal dysplasia |
| Whole eye syndrome | Rubella |
| | Microphthalmos |
| Glaucoma | eg. Lowe's syndrome |
| | Rubella |

Even when other abnormalities are present, the cataract may contribute significantly towards the visual impairment and the child may benefit from cataract surgery. Associate anomalies may affect

the choice of surgical procedure e.g. a microphthalmic eye will be too small for an intraocular lens, and some surgeons would not use an IOL in congenital rubella syndrome, because of the high risk of inflammation.

## Examination techniques

Pupil responses should be normal in the absence of co-existing pathology. Poor pupil reactions should increase suspicion of a posterior segment problem. Detailed examination of the anterior segment and vitreous of young children is difficult even with a portable slit lamp. Babies can sometimes be held with their chins on adult slit lamps but this is difficult with older children. Alternatives include a loupe and flashlight; 20D lenses used as magnifiers with a flashlight or a conventional indirect ophthalmoscope viewing from a closer distance than for fundoscopy (leaves one hand free to hold lids etc); or a direct ophthalmoscope with the maximum plus lens for magnification. The retina should be examined with an indirect ophthalmoscope through a dilated pupil. If no clear view is obtainable then a B-scan ultrasound may be helpful. Retinoscopy, when possible, may give useful clues about the size of the eye, and the density of the lens opacities.

# Systemic assessment

It must be remembered that children have died under general anaesthetic for cataract surgery. All children for whom surgery has been planned must undergo appropriate systemic medical assessment and judged to be fit to undergo general anaesthetic prior to surgery, as outlined in previous sections.

# Diagnosis of congenital cataract, and indications for surgery

## Dense bilateral congenital cataracts

If a child is born with dense bilateral cataracts, ideally surgery and aphakic correction should be completed by 6 weeks of age. If treatment is performed later than this the child is likely to develop nystagmus and amblyopia. The severity of the amblyopia increases with increasing delay in treatment.

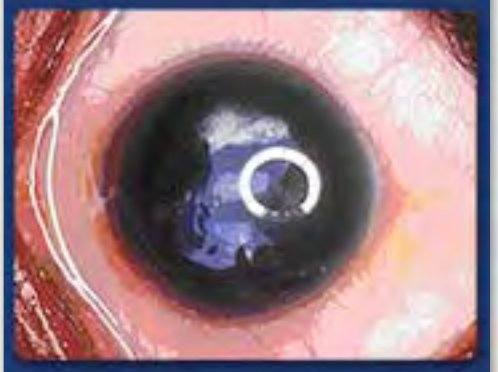
If a child presents later, often with nystagmus already established, and the cataracts are both dense, then cataract surgery is still worthwhile and should be performed without further delay. Acuity results will frequently be poor due to established amblyopia, especially if the child is more than 6 months old. However, the child will benefit from improved navigational vision.

Early surgery is likely to give the best visual results, but it also carries greater risks, particularly in the absence of specialist facilities for anaesthetising small babies. Furthermore, earlier surgery increases the risk of later glaucoma. In Africa it is necessary to strike a balance between achieving the best possible vision, and minimizing the risks of surgery and late complications.

## Unilateral cataracts

Unilateral cataracts present a problem because visual outcome is generally poor even in developed countries.  In order to improve visual outcomes early surgery and intensive patching are necessary but early surgery may put the child at increased risk from GA (general anaesthetic) for minimal benefit to the child's life and is therefore usually inappropriate. Later surgery may be appropriate when the GA risk is less as long as the limited prognosis is well understood.  The benefits may include

**Zonular Cataract**
The nucleus is not totally opaque, and the surrounding lens cortex is clear. This eye has 6/24 vision.



**Total Cataract**
The lens remnant is shrunken and fibrotic. This eye has a vision of hand motions.

acquisition of navigational vision and cosmetic improvement. Most surgeons in developing countries advise against operating on unilateral cataracts below the age of 6 months because of the GA risk even though this sacrifices visual outcome.

## Bilateral partial congenital cataracts

Deciding whether or when to operate is easy for dense bilateral cataracts. It is harder to decide on optimum timing of surgery in partial cataracts in Africa. In a very small sleepy infant it may be difficult to perform acuity testing. If the results are uncertain, the best course of action it is to wait and reassess the child soon. If nystagmus is developing the optimum time for surgery may have already been missed, so act quickly. However, a note of caution is that the eye may have nystagmus not only because of the lens opacity but also because of associated ocular anomalies (e.g. optic nerve hypoplasia) which may co-exist, particularly in small eyes. If the child has a squint, consider occlusion therapy of the preferred eye, especially if the opacities appear asymmetrical. Refract the eyes. Occasionally marked refractive errors are found and spectacle prescription can be helpful, particularly in myopic errors. Noting the ease of obtaining a reflex is one of the ways of monitoring the increasing density of the opacity. However, lamellar opacity in developmental cataract can be consistent with surprisingly good acuity in eyes in which it is impossible to obtain a retinoscopy reflex.

The morphology of the opacities is very important. Anterior polar opacities rarely require surgical intervention, but, if asymmetrical, consider occlusion therapy and always refract, as there may be associated refractive error. Lamellar or zonular opacity, and opacities made up of scattered dots, in developmental cataract often progress slowly and are consistent with good vision. Frequently these opacities gradually increase and a child may begin to lose vision around the age of 5 years, when, if implant surgery is available, this should be considered with over-correction with glasses.

Posterior cataracts are usually very amblyogenic in infants.

## Traumatic Cataracts

The individual situation varies so much in trauma that it is difficult to give general advice. In most cataract associated with penetrating trauma, especially when the risk of infection is high, primary repair generally does not include removal of the lens. The lens is removed once the eye is quieter and an in-the-bag or sulcus-fixated intraocular lens can then be considered. Anterior chamber lenses should not be used in children.

The major advantage of early cataract surgery is the reduction in amblyopia and, if this was the only consideration, the “earlier the better” would be the rule. However, there are risks associated with early surgery.

## Hazards of early surgery

- The risks of general anaesthesia are higher in a small infant
- Surgery is technically more difficult: the pupil doesn’t dilate well, the iris is more vascular, and the capsular bag is smaller
- The inflammatory response is greater
- The risk of early and late onset aphakic glaucoma is much higher – up to 25% in some series
- The future growth of the eye cannot be calculated so that if lens implantation is considered, glasses or contact lenses will always be required in addition
- As complications are common, and refractive changes are rapid, monitoring must be frequent
- If there is a delay between surgery on the first and second eyes, amblyopia is likely unless occlusion therapy is used on the first eye. Increased risk of fibrinous uveitis has been noted by some if the delay between the eyes is 2-3 weeks as opposed to 1 week which is another reason not to delay beyond one week between eyes if possible.

To address these hazards:

- Work with an anaesthetist experienced in care of the young child, and make sure monitoring is available for 24 hours postoperatively
- If the iris is very vascular, wait until the baby is one month old
- Take care that all lens matter is carefully aspirated and that an adequate anterior vitrectomy is performed

## Bilateral simultaneous surgery

Because of the small but potentially catastrophic risk of endophthalmitis separate procedures are generally recommended spaced apart by about 1 week (during the same admission). If the anaesthetist judges the risk of 2 separate procedures to be significantly greater than one longer procedure then bilateral simultaneous surgery could be considered. In this case re-preparation and change of instruments between the surgeries should be performed to minimize risk of infection.

| | Earlier surgery | Later surgery |
|---|---|---|
| Advantages | Reduced risk of amblyopia<br>Reduced risk of nystagmus | Reduced glaucoma risk?<br>Easier visual rehabilitation<br>Vision testing easier<br>Reduced inflammation<br>Less capsule opacity |
| Disadvantages | Glaucoma risk higher?<br>Anaesthetic risk increased<br>Technically more difficult, given the smaller eye | Increased amblyopia risk<br>Increased nystagmus<br>General childhood development slowed |

# SURGERY OF CHILDHOOD CATARACT

Childhood cataracts are surgically more challenging than adult cataracts. The anterior chamber tends to shallow with vitreous pressure. The eye is smaller and often there is associated microcornea. The lens capsule is more elastic than in adult eyes and this makes a capsulorhexis more difficult. In general trained paediatric ophthalmologists (or other ophthalmologists who have been trained in paediatric cataract surgery) should operate on all of these children.

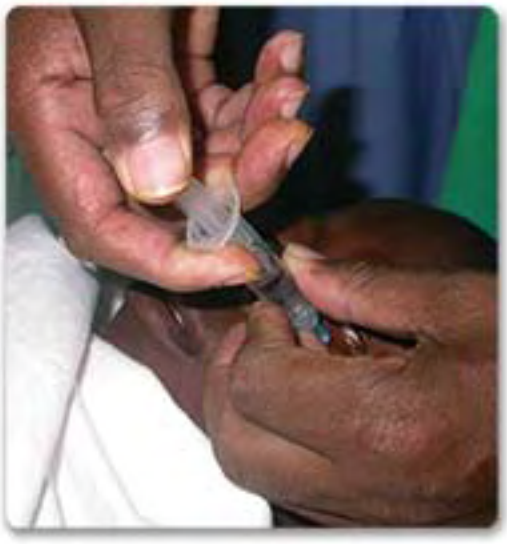
General anaesthesia with muscle relaxants is recommended. If not available, ketamine is possible but makes surgery more difficult (because of positive pressure from the vitreous) and should be accompanied by peribulbar anaesthesia and requires quick surgery.

# Pre-operative preparation

The eyes and general health should be fully assessed, as outlined in previous chapters. It is important to re-emphasize that the child should be examined by the anaesthetist in order to be sure that a general anaesthetic will be safe, as congenital cataract can be associated with cardiac and other anomalies.

Again, the importance of the family's dedication to good follow up should be emphasized, as frequent clinic visits, subsequent treatments and operations are sometimes required. At the same time, they should be encouraged that many children with congenital cataract, who receive prompt and effective treatment, grow up to lead perfectly normal lives. In the end, the family's commitment will be rewarded.

# Surgical technique



Many different surgical techniques have been used in the past to treat childhood cataract: In Africa where follow up may be uncertain there are 2 general principles to observe:

- Insert an IOL where possible (there is evidence that compliance with aphakic spectacles is very difficult and contact lenses are usually impossible, making IOLs the most practical form of optical rehabilitation)
- Perform primary posterior capsulotomy and anterior vitrectomy in almost all cases. (There is evidence even in children over the age of 7 that high rates of PCO occur if these steps not performed.)

Exceptions to the 2 general principles of surgical technique include:

- Some surgeons feel that IOL insertion should be delayed until a certain age which may vary from 9 months to 2 years whereas others prefer primary implantation even in infancy. This choice may depend on surgical experience and type of IOL available and should be left to the individual surgeon in the absence of clear evidence either way.
- If children are aged over 10, and YAG capsulotomy will be possible (i.e. slit lamp compliant, no nystagmus, and live locally) then the surgeon may reasonably perform lens aspiration and IOL insertion leaving the posterior capsule and vitreous intact.

# Technical points

## Wound

A scleral tunnel, or a clear corneal incision are both possible. Although in adults these incisions may be watertight without sutures, in young children the natural scleral elasticity tends to pull the wound open, and sutures will be necessary. Because the child's eye is more collapsible it is important to minimize the size of the internal wound entering the AC (e.g. only large enough to accommodate the instrument to be used for aspiration) until placing the lens. Paracenteses are normally used to aid cortex aspiration through 360 degrees and to place an AC maintainer if used.

## Anterior capsulotomy

Continuous curvilinear capsulorhexis is difficult in young children, even with the use of visco-elastic and/or trypan blue. The anterior capsule is more elastic than in adults, and tends to be more convex. It is best to keep the capsulorhexis small, as the lens matter can usually be aspirated easily. An alternative is to use a vitrectomy instrument to remove the anterior capsule. This also provides a continuous anterior capsule margin, but it is less resistant to tearing than a capsulorhexis. Can-opener / slit anterior capsulotomies may be used but may result in smaller chance of 'in the bag' fixation.

## Lens aspiration

A variety of techniques may be used including standard Simcoe aspiration; a separate AC maintainer infusion using vitrectomy cutter to aspirate; or use of aspiration mode with a phaco probe.

## Posterior capsule

Options include manual posterior capsulorhexis or capsulectomy with a vitreous cutter. Both techniques can be performed before or after IOL insertion according to surgeon preference. Both techniques should also be accompanied by anterior vitrectomy, which may be done, via an anterior or pars plana approach. Currently there is no evidence to separate any of these techniques and surgeons should choose that which they are most comfortable with.

## Peri-operative medication

There is evidence that intracameral cephalosporin injections at the end of the surgery reduce risk of endophthalmitis in adults and we have used it safely in children. In addition to routine subconjunctival dexamethesone and antibiotic we also recommend subconjunctival depot steroid such as triamcinolone or depomedrone (20mg).
Post-operative topical steroids should be given frequently (one or two hourly) and four hourly antibiotic. Cycloplegia is generally recommended and should not increase risk of optic capture by pupil if in - the - bag fixation is certain.

## Wound closure

Even tunnel wounds that could safely be left sutureless in adults require suturing in children. Paracenteses can usually be left unsutured though hydroinflation and placing an air bubble in the AC may help ensure watertightness in babies under 6 months suturing of paracenteses is advisable.

# IOL selection

The insertion of an intra-ocular lens is a routine part of cataract surgery in adults, even in many developing countries. It is now over fifty years since the first IOL was implanted. However, until recently, IOL were not widely used in children.

As the safety of IOL in adults has become increasingly accepted, there has been a growing willingness to use IOL in children as well. It is now routine to use IOL in children over five years old, and they are frequently used in children between two and five years. This is because the eye

changes very rapidly in young children. In a three-month-old baby, an IOL power of 28-30D may be required for emmetropia. However, this is likely to lead to significant myopia in later life. Unlike a spectacle lens or contact lens, it is not simple to change the power of an IOL. Secondly, the diameter of the lens in an infant is 2mm less than an adult lens. This makes it difficult to implant a standard adult IOL into the capsular bag. The maximum diameter of the IOL should not exceed 12 mm. Smaller IOL designed for use in children can be obtained.

While an IOL corrects the aphakia, it does not correct astigmatism, and there will almost certainly be some residual spherical error. This means that spectacles will still be necessary in order to obtain best-corrected vision, especially for near. These spectacles will be lighter, and easier to wear, than the thick lenses required for spectacle correction of aphakia. As they are relatively low powered lenses, there are fewer optical aberrations. Although IOL use appears to be safe in children over two years, there is an increased incidence of post-operative uveitis, particularly in heavily pigmented eyes. Some eyes are unsuitable for IOL insertion. If the corneal diameter is less than 9mm, an IOL should not be implanted. Eyes with chronic uveitis – associated with juvenile rheumatoid arthritis, for example – should not have an IOL, as the presence of an IOL may exacerbate the intraocular inflammation.

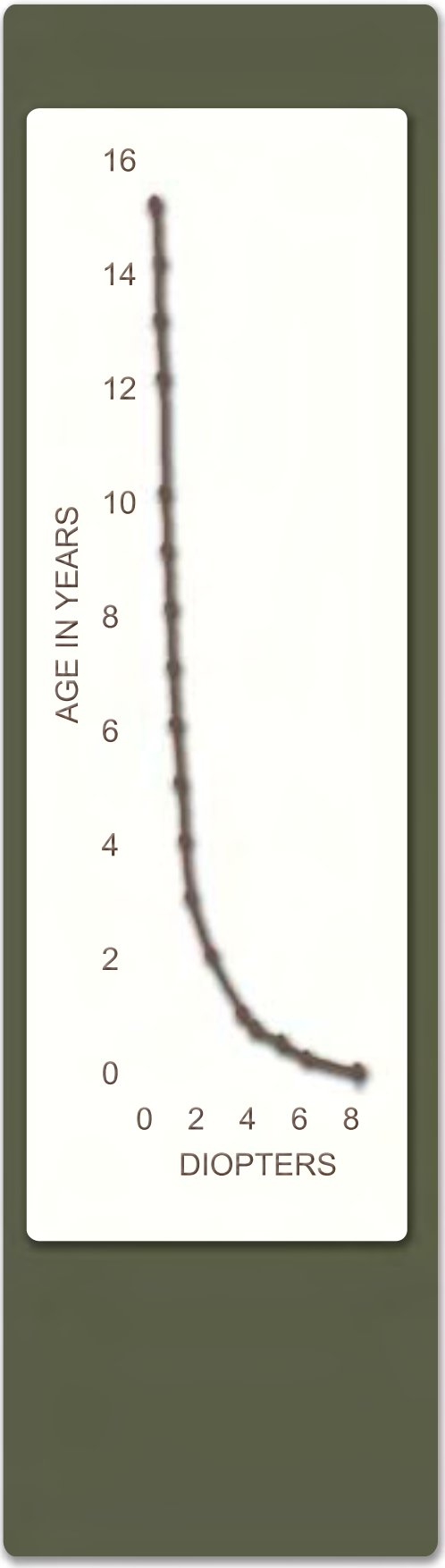
The major advantage of an IOL is that it provides permanent continuous correction of the aphakia. This may be important in preventing amblyopia, and encouraging normal visual development. Although glasses are necessary to obtain the best vision, uncorrected pseudophakic vision is likely to be significantly better than uncorrected aphakic vision.

Numerous different materials and designs of intraocular lens (IOL) are available. Although anterior chamber lenses have been shown to be safe and effective in adults, there is no evidence

confirming their safety in children. We recommend that anterior chamber lenses should not be used in children at this time. Polymethyl methacrylate (PMMA) has been the material of choice for all IOL until recently. There are now silicon IOL, hydrophilic acrylic IOL, and hydrogel IOL. Some of these new materials may have specific advantages in children, particularly increased biocompatibility, and a reduced risk of uveitis. However, this has not yet been proven. Before inserting an IOL made of a newer material, consider that it may need to last for 60 years, and we have barely ten years experience of most of the newer IOL materials compared to 50 years experience of PMMA. The most difficult question is what power of IOL to use.

## Biometry

Children of 5 and over should have biometry attempted while they are awake prior to surgery. In younger or uncooperative children a portable keratometer and A scanner should be available in theatre to conduct biometry after induction.




## Calculation

In children over five years, where biometry is available, the IOL that will come closest to emmetropia should be used. If biometry is not available, and there is no information on the previous refractive state of the eye, then the standard power adult IOL (usually 21-22 D) should be used. In children between two and five, it is usual to leave them with 1-2 D of hypermetropia, as this should come close to emmetropia later in life. If no biometry is available, a 23 - 24 D IOL is used.

In children less than two there is no clear consensus regarding appropriate IOL power. Correction of aphakia in an infant will probably require a 28-30 D IOL. This is likely to lead to myopia in later life. It is currently recommended that children under two should have an IOL with a 20% under correction. This means that if biometry shows that the child needs a 30 D IOL, a 24 D IOL is inserted. The disadvantage of this is that it leaves the child with significant hypermetropia, which may lead to a blurred retinal image and abnormal visual development. Wilson has suggested the following guide for choice of IOL power when axial length is available without keratometry.

Even with an IOL, children will have no accommodation, and it is important to provide an additional near correction (+2,50-3.00D on top of cycloplegic refraction) for infants whose visual world is near or bifocals, for older children.

| Axial length (mm) | IOL power (diopters) |
|---|---|
| 17 | 28 |
| 18 | 27 |
| 19 | 26 |
| 20 | 24 |
| 21 | 22 |

# Complications of surgery

The risk of complications during surgery in infant eyes is higher than that in adult eyes. Insufficient removal of cortical material may be a consequence of aspiration techniques; posterior capsule opacification becomes more likely and increases postoperative inflammation.

Vitreous attachments to entry site may be a problem in any procedure after the vitreous has been disturbed; infection and epithelial in-growth become more likely. This complication is less likely after pars plana anterior vitrectomy as opposed to an anterior approach.

## Early complications

The early complications of cataract surgery are much the same in children and adults – wound leaks, endophthalmitis, raised intra-ocular pressure etc. Unfortunately, in children it can be very difficult to examine the eye fully the day after cataract surgery, and it may be necessary to carry out an examination under anaesthesia.

Following IOL insertion, children – particularly children with a heavily pigmented iris – are much more likely to develop a severe fibrinous uveitis than adult cataract patients. The uveitis usually occurs three to seven days after cataract surgery. The risk of uveitis can be reduced by using heparin surface modified IOLs, or by using some of the newer IOL materials, such as acrylic IOLs. The uveitis can usually be controlled by topical steroids alone, and all children should be placed on frequent topical steroids as a routine post-operatively. The steroids should be tailed off gradually over four to six weeks. There is no evidence that systemic steroids are superior to intensive topical steroids in this situation, and they carry a much greater risk of severe side effects. Occasionally a dense fibrous

membrane will occlude the pupil, and may require surgical removal. As fibrinous uveitis can occur in 30-40% of children following IOL insertion, it may be safer to keep them in hospital for a week after surgery, to facilitate early diagnosis and treatment.

Certain types of cataract – particularly cataract associated with congenital rubella – are at higher risk of post-operative uveitis. If the cataract is thought to be due to uveitis – eg. juvenile rheumatoid arthritis – this is an absolute contra-indication to IOL implantation.

## Late complications

## Posterior capsule opacification

If a lensectomy has been performed, posterior capsule opacification should not occur, however, occasionally pearls of soft lens matter will grow at the edge of any residual capsule, and these can occlude the visual axis. If the child has not had the posterior capsule removed at surgery, it will become opaque at some time. Posterior capsule opacity is universal following cataract surgery in children. In young children, who may become amblyopic before capsule opacity is detected, this is a strong argument for doing a posterior capsulectomy at the time of cataract surgery. In older children, who can be examined more easily, and who are at less risk of amblyopia, capsule opacity can be detected and treated as it occurs. Recognition of posterior capsule opacity is usually easy, as the red reflex becomes obscured. It may be necessary to dilate the pupil to confirm the diagnosis.

The posterior capsule can be opened with an Nd:YAG laser, however, this equipment is not yet widely available in developing countries. In young children, the lens epithelial cells can re-proliferate on the anterior vitreous face even after Nd:YAG capsulotomy, so treatment may need to be repeated. Young children may not tolerate the use of a contact lens at a slit lamp, and they may need a laser that has been modified to work with an operating microscope so that it can be used on anaesthetised patients.

An alternative method is to use a vitrectomy cutter to remove the posterior capsule and the anterior vitreous. This usually provides a permanent solution to capsule opacity, but carries the risks associated with all intra-ocular surgery and general anaesthesia. It is best to insert the cutter through the pars plana to avoid the risk of vitreous incarceration in a limbal or corneal wound. At present there is no means of preventing posterior capsule opacification in children, although good surgical technique, and the use of well-designed IOLs may delay its onset.

## Glaucoma

Following surgery for congenital cataract, up to 25% of children may develop glaucoma. The glaucoma usually occurs a few years after cataract surgery. The risk of glaucoma is greatest in children that have had a lensectomy during the first four weeks of life. It is also more frequent in certain types of cataract – Lowe's syndrome, congenital rubella, microphthalmic eyes. The diagnosis of glaucoma in young children can be very difficult. Measuring IOP may require general anaesthesia. Important clues to the onset of glaucoma are increasing corneal diameter, and increasing myopic shift in the refraction. Examination of the disc will reveal pathological cupping. Treatment of glaucoma in children is also difficult. Many will require cyclodestructive procedures to control the IOP. Glaucoma surgery is less effective in children than adults.

## Retinal detachment

This is usually delayed, and the maximum incidence appears to be about 20 years after cataract surgery. This makes it difficult to say whether or not changes in surgical techniques introduced over the last twenty years will reduce the incidence of retinal detachment.

Retinal detachment can be difficult to detect. If there is nystagmus, a small pupil, and residual capsule and lens matter it can be very difficult to examine the retina. Always suspect retinal detachment in childhood cataract patients who have sudden loss of vision. Repair of the detachment usually leads to a significant improvement in vision, even if the macula has been detached. These patients should be referred to the nearest retinal surgeon.

# Expected outcomes

In adult patients, the WHO has set guidelines suggesting that at least 90% of patients should achieve a best-corrected vision of 6/18 or better, and no more than 5% should have less than 6/60 vision. These targets would be very difficult to achieve in young children in Africa.

The prognosis for any infant with a cataract is unpredictable. Although the initial results may be excellent, the eye may become amblyopic, leading to a poor outcome. The final visual result in adults is known within a few months of surgery. However, in an infant, the final vision cannot be known with any certainty until the child is 5-6 years old, and the risk of amblyopia diminishes. Secondly, the vision may take months to improve.

In general, children who develop cataract before the age of two will have a worse prognosis. Secondly, total cataracts, as opposed to zonular or lamellar lens opacities, will have a worse prognosis. Finally, associated abnormalities, such as corneal opacity, or optic atrophy, will reduce the probability of a good outcome.

If the guidelines in this manual are implemented, we believe that it is reasonable to set the following targets for visual outcomes:

Children under two years old
- <10% less than 6/60
- >50% 6/18 or better

Children over two years old
- <5% less than 6/60
- >70% 6/18 or better

These targets are to be used with caution. Better outcomes are certainly possible, and, if a clinic is already achieving these results, we recommend that new, and more ambitious targets should be set. The key point is not to achieve an arbitrary target, but to monitor and evaluate outcomes, and to have a process of continuous quality improvement.

# POST OPERATIVE SERVICES FOR CHILDREN WITH CATARACT

The aims of post-operative care are both to maximize the benefits of any surgical procedure, and to minimize the risks posed by early or delayed post-operative complications. This is particularly true of surgery for cataract in children. The frequency of post-operative care depends upon the age of the child.

| Age of child | Location | Frequency of follow up |
|---|---|---|
| Zero to 3 years old | CEHTF | One week after discharge (if child lives far from the CEHTF, it maybe best to keep the child for a week)<br>Within 3 months<br>At 3 months |
| | District CEHTF | After 6 months, 4 times per year<br>Once per year |
| Four years and older | CEHTF | One week after discharge (if child lives far from the CEHTF, it maybe best to keep the child for a week)<br>Within 6 weeks |
| | District | At 3 months<br>At 6 months<br>After 6 months, 2 times per year |

# Team based approach

For postoperative care in Africa to be carried out properly, a (multi-disciplinary) team-based approach is necessary. This will enable all of the many different needs of the child and the family to be met. Ideally the team should consist of the following:

- Ophthalmologist – providing the surgical service
- Childhood Blindness and Low Vision Coordinator – coordinating all services needed by children identified for surgery, counseling, follow up, etc.
- Orthoptist – to monitor visual acuity in young children, detect and treat amblyopia and squint
- Optometrist – with expertise in childhood aphakia and pseudophakia, to refract and provide appropriate correction for refractive errors
- Low vision worker (either orthoptist, optometrist or educator) – to assist children who have residual visual handicap, visual stimulation
- Education advisor – to ensure that the child receives appropriate education, and obtains additional educational support if necessary
- Paediatrician – to deal with any associated illnesses or disabilities
- Anaesthetist – with expertise in anaesthetising small babies

Some of the skills listed above can be combined in one person / job.

Finally, parents provide the day-to-day care of the child and play a key role in the post-operative care of children with cataracts. They have to instill the eye drops, bring the child to the clinics, pay for spectacles, ensure compliance with occlusion regimes, and ensure regular follow-up. It is critically important that they are involved and welcomed as members of the team. Unless they are wholly committed to the post-operative care of the child, treatment is unlikely to succeed.

Usually it will not be feasible to have all of them available all of the time. However, every CEHTF that carries out cataract surgery in children should ensure that they have established a team including all of the skills above.

The focus of post-operative care of children is four-fold:

- Clinical examination for assessment of post-operative complications
- Refraction and low vision assessment
- Amblyopia treatment
- Assessment for recommendations for educational placement

At the district hospital an additional focus of post-operative care of children is consideration for referral to the CEHTF if any complications are detected.

# Achieving good follow up in Africa

Achieving good follow up requires a number of specific activities, generally within the job description of the “Childhood Blindness and Low Vision Coordinator”. Poor follow up is NOT inevitable; there is clear evidence that good follow up can be achieved if specific strategies are put in place.

## Childhood Cataract Tracking Form

At the time of surgery a “Childhood Cataract Tracking Form” (see Appendix IV) should be created for each child. The tracking form is the primary tool to assist all involved in clinical and educational management of the child to ensure that proper follow up is achieved. The form includes expected dates of follow up and the anticipated activities at the follow up visit. Contact information for the parents (or nearby residents), particularly a (cell) phone number is essential. It is always helpful to draw a map of the location of the residence.

## Counseling of the parents

Counseling at the time of discharge (described in a previous section) is essential for ensuring that parents and/or guardians have a clear understanding of their role in ensuring that their child receives necessary follow up services. Without proper counseling parents often think that surgery is the final component of service for their child.

## Letter/form given to parent describing follow up dates & activities

Every parent should be given a letter or form describing the need for follow up and what is to be expected to occur at the time of follow up. The letter should include the date of the next follow up visit as well as the (cell) phone number of the Childhood Blindness and Low Vision Coordinator. It is recommended that (when necessary) details regarding reimbursement of transport expenses is included on the letter. The letter should also include details of local eye care providers who have been trained.

## Use of (cell) phones to remind parents of follow up

It has been shown that reminding parents through use of a cell phone call improves follow up considerably. It is essential that a phone number (even if only local shopkeeper) be recorded. Parents appreciate a reminder; it shows them that there are people interested in the welfare of their children.

## Reimbursement of transportation expenses

In many African setting, transportation expenses are quite high, particularly for people living quite distant from a CEHTF. In these situations it has been shown that reimbursement of transportation expenses has been required to ensure good follow up.

## Training of health personnel external to the CEHTF

Good follow up requires support from facilities external to the CEHTF. Not only will "district" facilities provide some specific follow up activities, these facilities are also essential for continuing a connection between the family and the health care facility. This connection is essential to the concept of VISION 2020—that is, the health and well being of people living in a defined VISION 2020 "district" are the responsibility of the VISION 2020 implementation team. This is true, regardless of where the child actually gets surgery. Engendering this perspective requires training of eye health personnel external to the CEHTF. This training should focus on the following messages/skills:

1. The standard follow up guidelines (as noted above)
2. The skills in post operative examination (protocol for examination, etc.)
3. The refractive and low vision needs of children following cataract surgery
4. Appropriate educational placement following surgery (and their role in assisting placement and needs)
5. The need for district eye health staff to remain in close communication with the "Childhood Blindness and Low Vision Coordinator" regarding individual children

# Refraction

Proper refraction of very young children is important, requiring more follow up visits at a CEHTF, compared to older children. Refraction is an essential part of follow up at the visits in italics below.

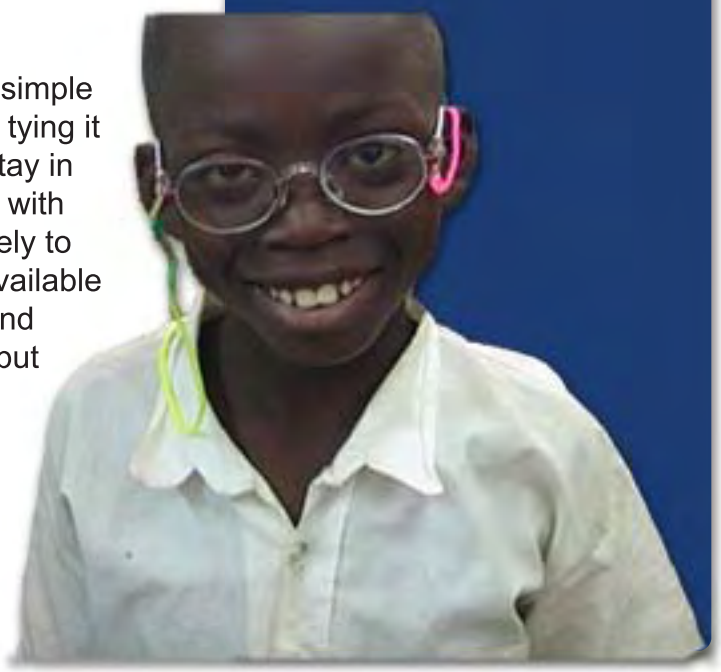
| Age of child | Location | Frequency of follow up |
|---|---|---|
| Zero to 3 years old | CEHTF | One week after discharge (if child lives far from the CEHTF, it maybe best to keep the child for a week)<br>Within 3 months<br>*At 3 months* |
| | District CEHTF | *After 6 months, 4 times per year*<br>*Once per year* |
| Four years and older | CEHTF | One week after discharge (if child lives far from the CEHTF, it maybe best to keep the child for a week)<br>*Within 6 weeks* |
| | District | *At 3 months*<br>*At 6 months*<br>*After 6 months, 2 times per year* |

Removing the cataract will not improve vision unless the refractive error is fully and accurately corrected. In infants, the hypermetropia of +16 to +20 D corrections are not uncommon. This means that the retinal image is out of focus. A defocused retinal image will lead to abnormal visual development, including amblyopia and nystagmus. In adults, if aphakic correction is not given soon after surgery, the eye will not see clearly. However, if the aphakic correction is provided at a later date, the vision will immediately improve. In children less than five years, if aphakic correction is not provided immediately, normal visual development will not occur, and visual function will be

permanently lost, even if full aphakic correction is provided later. This means that no child should have cataract surgery unless there is a realistic plan for correcting their aphakia post-operatively. In Africa two options for correcting aphakia are implantation of an intraocular lens and/or spectacle correction. IOL implantation has been described in the previous chapter.

Spectacle correction will generally be required, regardless of the IOL implant. As the eye grows, its refractive state will change, and the refractive correction will also change. There are problems however with using glasses in aphakic children; children are mobile and active, and glasses are likely to get lost or broken. Replacing them can be costly. Because infants may require a correction of +18 dioptres, their glasses are often heavy and uncomfortable. It is difficult to fit children less than two years with glasses that they will wear continuously. If they do not wear their glasses, they will see very little, and may not develop normal vision. Aphakic spectacles in children suffer from the same optical disadvantages as aphakic spectacles in adults. The image is enlarged and distorted, and there is a limited field of view. This may be a considerable handicap for an active child.

## Prescription of glasses



Frames should be robust. In infants, a simple plastic frame, which is held in place by tying it behind the head, is the most likely to stay in place. In slightly older children, frames with wire curls behind the ears are more likely to stay in position. If plastic lenses are available they should be used – they are safer and lighter. They will get badly scratched, but the glasses will need to be replaced regularly anyway. Hard cases are recommended for protection of all types of glasses. Children under five years old do not require perfect long distance vision, as most of the objects in which they are interested

will be close to them – their mother's face, or a favourite toy, for example. As the children need good near vision, it is best to over-correct the aphakia slightly, by 2 D in a child under two, and by 1 D in a child between two and five years. Under correction can lead to accommodative esotropia, and increased risk of amblyopia.

Older children must be able to function normally at school. This means having good vision for both distance and near. Removing the lens also removes any ability to accommodate, so these children will need bifocal glasses. If bifocals are used, the position of the reading segment needs to be 1-2mm higher than it is in an adult, level with the lower edge of the pupil rather than the lower edge of the cornea. Many aphakic children will have reduced visual acuity. They may find it easier to read normal sized reading print if they have a +4 - +8 reading addition, and hold the print correspondingly closer to their eyes.

Successful surgery will have restored a clear visual axis, however, until the child's refractive error is fully corrected, there will be little visual benefit from this. This means that the child should have refraction at four to six weeks after surgery, or even sooner in an infant. Because infants' eyes are growing and developing rapidly, refraction must be carried out more frequently than in older children. In principle all refractive error should be corrected, particularly in infants.

In children up to three years old, give glasses with an additional +3 dioptres, as the child needs good near vision in order to focus parents' faces, toys, etc. Over 3 years, bifocal spectacles may be used. The near addition should be +4, as children hold objects closer than adults. The near segment must be higher than in adults.

All CEHTF need to stock a variety of frames in children's sizes. Recommendations for stocking of spectacles can be calculated as follows:

- For children 0-3 years of age, 2 pairs of glasses per year
- For children 4 years of age and older, 1 new pair of glasses per year

For young children it is recommended that glasses giving intermediate working distance be provided. For reading / writing the choices are:

- bifocals
- distance correction with low power (4 – 6 D) hand magnifier
- 2 pairs of glasses: distance corrections + glasses for near

Obtaining the glasses prescribed is an often overlooked last step, and needs a structured system whereby eye care staff ensure glasses are obtained and worn. Childern and parents should be instructed on how to wear, and care for the glasses.

## Amblyopia

In children under five years, cataract may be associated with amblyopia in one or both eyes, as described in the first section. The diagnosis of amblyopia is usually based on a reduction of vision in an eye for which there is no other explanation. Unfortunately there is no simple test to confirm or exclude amblyopia. Since accurate measurement of visual acuity in young children may be difficult, we may have to rely on the observation that there is a difference in the vision between the two eyes, i.e., that the child prefers to use one eye over the other, to diagnose amblyopia. Visual acuity testing in small children is only an estimate of the vision, so minor differences in vision are best ignored. A difference of two lines of Snellen acuity, or 0.3 LogMAR units, is usually indicative of a significant difference in vision between the two eyes. Amblyopia can only be treated when the vision in the eye has been maximized by full correction of any refractive error.

Amblyopia is normally treated by occluding the preferred eye in order to force the child to use the amblyopic or “lazy” eye. The most common method of occlusion is to place an adhesive patch over the preferred eye. Alternatives include frosted glass, or opaque spectacle lenses, or blurring the vision with atropine drops (this is of doubtful effectiveness in aphakic children). Again, the younger the child, the more sensitive they are to amblyopia treatment. An infant may only require occlusion for a few hours every day, but a child of five years may need continuous occlusion during all waking hours. A schedule of occlusion therapy is given in the following table.

| Visual acuity difference | Occlusion regime |
|---|---|
| Zero to 1 line difference | No occlusion |
| Two to 3 lines difference | Patch preferred eye 1-2 hours per day |
| More than 3 lines difference | Patch preferred eye 2-4 hours per day |
| If not improvement after 2-4 hours occlusion | Patch full time |

# Low vision assessment and service

Every child who has surgery for cataract should have a detailed low vision assessment. As refraction and prescription of corrective glasses always is needed before the low vision assessment and has a direct effect, on for example, the need for magnification, the low vision assessment ideally should be done by the same person performing the refraction.

Some of the assessment therefore listed below might already take place during the eye examination and refraction (such as binocular vision) and can then be omitted from the list below. Low vision assessment should be done at the same time refraction is performed or shortly after the refraction, when the child is wearing the new distance glasses.

## Children 0-3 years of age

For children 0 to 3 years of age, the low vision assessment should include the following activities (after refraction and in addition to possible occlusion therapy):

- Assessment of near vision, including size of and distance at which objects are seen (as most of the activities the child needs to learn about are at near and intermediate distances); it is advisable to use a test comparable to the one used for distance acuity measurement.
- It is important to encourage a child to use (near) vision, while wearing the glasses (with + 3 D addition)
- Binocular vision: However subjective assessment of binocular vision is not always possible to assess in this age group.
- Basic visual skills such as fixation, tracking, tracing, scanning and eye-hand coordination
- Basic lighting needs, including measures to maximize use of available light and control of glare
- Functional testing of contrast sensitivity, for example by presenting favourite toys or food utensils against different backgrounds, in order to give advice on best use of contrast in daily activities at home, for each individual child
- Overall advice on best use of size, distance, light, colour, contrast and positioning of objects so the child can maximize use of vision
- Advice on compensating for the limitations in field of vision caused by wearing glasses with high power lenses

## Children 4+ years of age

All (pre) school age children (from 4 years onwards) should be provided with the opportunity to attend (pre) school. It is estimated that 80% of children having surgery for cataract will require some low vision correction. By removing the lens they have lost the ability to accommodate and will require correction for reading. Thus, (pre) school age children need a more comprehensive low vision assessment; this should, in addition to the above, concentrate on:

- Regular refraction and prescription of bifocal glasses in both aphakic and pseudophakic cases
- The use of vision for reading and writing, as the demand on these near vision activities increases with age and higher magnification might be required for older children
- Prescription of magnification, if needed, in addition to the correction prescribed, preferably in the form of high + glasses or a large size, robust, stand magnifier for young children; older children can learn to use a variety of devices
- Ability to access information written on the blackboard, be it through the use of reader and/or a telescope and/or sitting closer to the blackboard
- Clinical (and if not possible, functional) assessment of contrast sensitivity, as this is, amongst others, is related to reading ability and magnification
- Functional assessment of visual field
- Functional assessment of colour vision
- Advice on use of vision for outdoor play and mobility
- Non-optical interventions such as stand for writing, reading slit, cap, seating position near light

During the (bi) annual check up the eye examination, refraction and low vision assessment can be combined as one comprehensive follow-up.

## Skills required for low vision service delivery

The skills required by the low vision service provider at the CEHTF include the following:

- Retinoscopy and subjective refraction
- Assessment of visual functions, specifically near visual acuity, contrast sensitivity, lighting and field of vision
- Assessment of magnification needed
- Assessment of and training in the use of all different kinds of optical low vision devices for near and distance
- Assessment of and training in the use of non optical interventions
- Ability to translate all clinical low vision results and interventions into pragmatic and understandable information for the client, family and teachers

Low vision care at centres (e.g., district hospitals), mainly providing follow up care, is much more limited. Nevertheless, there are certain skills that the district low vision provider should be able to demonstrate. These include:

- Retinoscopy and subjective refraction
- Assessment of near visual acuity
- Assessment of magnification needed
- Assessment of and training in the use of basic optical low vision devices of low- medium power, such as for example microscopic glasses
- Advice on non optical interventions
- Ability to translate all clinical low vision results and interventions into pragmatic and understandable information for the client, family and teachers

## Equipment needed for low vision services

The equipment that a low vision technician has available depends upon the level of service provided. A low vision technician at a CEHTF will need a wider array of diagnostic equipment than someone providing basic low vision (follow up) at a district hospital.

| Equipment needed for low vision assessment at a CEHTF | Equipment needed for low vision follow up at a district hospital |
|---|---|
| Retinoscope | Retinoscope |
| Large aperture trial lens set | Usual trial lens set and trial frame |
| Children's size trial frame | |
| Variety of acuity tests for distance and near for all ages | |
| Contrast sensitivity test, e.g. LEA symbols | |
| Example of all non optical devices | Example of all non optical devices |
| Variety of optical low vision devices for near and distance | Basic set of low to medium power optical devices for near (as much as possible locally available: e.g. miscrocscopic glasses) |

Provision of optical and non-optical low vision devices is an essential part of the low vision service at a CEHTF. This requires that a basic stock of both optical and non-optical low vision devices be available. Similarly, at a district facility providing some follow up for low vision care will need to have some basic stocks. As clients might live quite far away, devices needed should, as much as possible, be available on the day of the assessment. Parents should be requested to contribute to the costs of the devices. Programmes should budget assuming that there will be a need for one device per year for the first two years that the child is in school. Recommended stocks will depend upon the number of surgeries being carried out per year.

# Guidelines for referral to education by eye care

Often people believe their child cannot go to school because of the visual problems or needs to go to a special blind school or resource centre. Too often eye care providers follow this idea and refer a child after surgery (back) to a blind school or resource centre.

Surgery can not only improve the vision of a child but also give the child a good chance to attend the local school. The first opportunity to discuss how the vision gained after surgery can be best used is during the first few follow up visits to the hospital. Therefore the ophthalmologist and optometrist/ low vision worker need to ensure that a child will access the local school as a matter of first choice. Most children operated for cataract will be able to access print, using their corrective glasses and/or low vision devices. The family needs to be shown (in practice) the size print their child can now see and what glasses and/or devices need to be used to facilitate this.

The following guidelines should ideally be followed:

- Every school age child needs to be referred to school (if not in currently attending)
- A link between eye care and district education / coordinator needs to be established to ensure each child is enrolled into the nearest school
- All children with low vision who can access print (small – large print size) should be referred to and enrolled in their local school rather than to a school for the blind

These children should receive the following support at school:

- Support from a special teacher / CBR worker / low vision worker is needed at the start of each school year (1 to 2 visits) to explain the needs of the child, and give advice on seating position, way of reading blackboard, use and care of glasses

devices, and overall support needed in the classroom
- Follow-up visits (2- 4 times a year) are recommended

Children with poor near vision who need Braille, should be referred to (in order of preference)

1. Local school, if regular support from itinerant teacher / CBR worker is available and access to Braille is organized.
   a. Informal training of classroom teacher, peers and school management is vital
   b. Regular follow-up visits and support by a special teacher is needed
2. Special school / resource centre / annex
   a. If Braille and regular support cannot be organised at the local school

Ideally the eye care centre should put a system in place for tracking the clients and their assimilation in the local school. This is helpful to:

- Ensure children use glasses and low vision devices
- Continue to encourage the parents and local school not to opt for a school for the blind (where Braille is the often the main learning medium)
- Facilitate annual follow-up at the eye care service for refraction, re-assessment of magnification, and effective use of available vision

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# LIST OF ABBREVIATIONS

| | |
|---|---|
| AC | Anterior Chamber |
| CEHTF | Child Eye Health Tertiary Facility |
| CSM | Central, Steady, Maintained |
| CT | Computerized Axial Tomography |
| D | Diopter |
| GA | General Anaesthetic |
| IgM | Immunoglobulin M |
| IOL | Intra-Ocular Lens |
| IOP | Intra-Ocular Pressure |
| YAG | Yttrium Aluminium Garnet |
| KCCO | Kilimanjaro Centre for Community Ophthalmology |
| KI | Key Informants |
| MAR | Minimum Angle of Resolution |
| Nd | Neodymium |
| NGO | Non-Government Organization |
| PCO | Posterior Capsular Opacity |
| PMMA | Poly (Methyl Methacrylate) |
| WHO | World Health Organization |

# APPENDIX I Summary from "Experts" Meeting

**Childhood Cataract "Experts" meeting, Moshi, KCMC, Tanzania**
**May 15-18th 2007**

Hosted & Coordinated by: Kilimanjaro Centre for Community Ophthalmology
Supported by: Dark & Light Blind Care

Summary

Recent evidence suggests that congenital and developmental cataract is the leading cause of blindness in children in much of Africa. Although data is limited it is likely that the backlog of surgery is around 100 children per million population and the annual incidence is probably around 20 children per million population per year.

WHO recommends that there be one paediatric ophthalmology tertiary centre per 10 million population; few countries of Africa have reached this target. Even in settings with tertiary centres few children are brought for surgery; those that are brought are generally brought too late to achieve the highest quality outcome of surgery. In most settings, girls number half that of boys. Virtually all children receiving surgery for congenital cataract in Africa will require long term follow up for spectacle correction and low vision care.

Tertiary facilities in Africa have strengthened the quality of the surgical service provided but have put little effort into promoting early identification and referral or into improving follow up, provision of spectacles, low vision care, or inclusive education. There are two facilities in Africa providing fellowship training in paediatric ophthalmology and one centre providing training in programme management for paediatric ophthalmology tertiary centres.

The Childhood Cataract Experts meeting brought together about 18 people from throughout Africa as well as key personnel from Europe and Asia to discuss potential solutions to the problems and to draft a practical manual on best practices for management of childhood cataract in Africa.

Recommendations

1. National Prevention of Blindness Committees are encouraged to identify (existing) paediatric ophthalmology tertiary centres and coordinate with them to define their respective catchment areas. According to WHO guidelines, these catchment areas should cover a population of approximately 10 million.
2. Existing data on childhood cataract from these catchment areas (age, sex, district of residence) should be compiled.
3. It is recommended that, for the purpose of planning and monitoring, a childhood cataract surgical rate (CCSR) be calculated for each VISION 2020 "district" (population 1-2 million, usually called "regions" or "provinces" in Africa). This information should be used to identify "districts" with low surgical coverage.
4. Evidence suggests that the use of key informants (at the community level) may increase identification and referral of children requiring surgery. Additional research is needed to test this method with other possible approaches.
5. In many countries there are still many children with cataract admitted to schools for the blind; national policies on admission of children to schools for blind (in particular, ophthalmologic examination prior to admission) are needed.
6. In most programmes that have achieved a significant increase in the number of surgeries in children, it has been necessary to waive surgical fees and to reimburse much of the travel expenses incurred by families to access surgery and follow up. These approaches may need to be adopted in most settings in Africa.
7. Although the exact timing of surgery depends upon the individual characteristics of the child, it is essential that all health care staff consider a "white" pupil in a child as an emergency and ensure that the child is seen by a paediatric ophthalmologist as soon as possible.
8. It is recommended that all children (in particular, younger children) only be operated on by paediatric ophthalmologists in well-equipped tertiary centres. These centres need to ensure high quality anaesthetic services.
9. Paediatric ophthalmology tertiary centres should have on staff a "Childhood Blindness Coordinator" responsible for counseling of parents (and children), organizing activities for early detection, training health staff, and conducting a tracking system to ensure that children are brought back for follow up, spectacles, and low vision care.
10. Every tertiary centre should have the facilities for the provision of spectacles and a low vision service.
11. Follow up after surgery is essential throughout childhood; strategies shown to be effective (counseling, recording and using cell phones for contact, reimbursement of transport costs, local eye care worker to visit family) should be adopted.
12. Refractive correction is be the single most important post-operative service children need and tertiary facilities must have strong optical services.
13. Low vision services and some refractive services (particularly for periodic changes in refractive error) should be decentralized as much as possible; relevant personnel in "districts" covered by the tertiary centre should be trained in back service delivery and be accountable for providing these services to children in their areas.
14. Successful low vision service provision requires strong links between the eye care and low vision service, accurate refraction, and near vision assessment. In addition, low vision services should have links with education and rehabilitation. In most settings, special education teachers and rehabilitation workers need training. Eye care providers need to take the lead for initiating and maintaining low vision and educational support.
15. A manual on the clinical and programme management of childhood cataract should be completed and disseminated as soon as possible.

# APPENDIX I Participants

**Managing Childhood Cataract in Africa:**
**Experts meeting**
**May 15-18, 2007**
**KCCO, Moshi, Tanzania**

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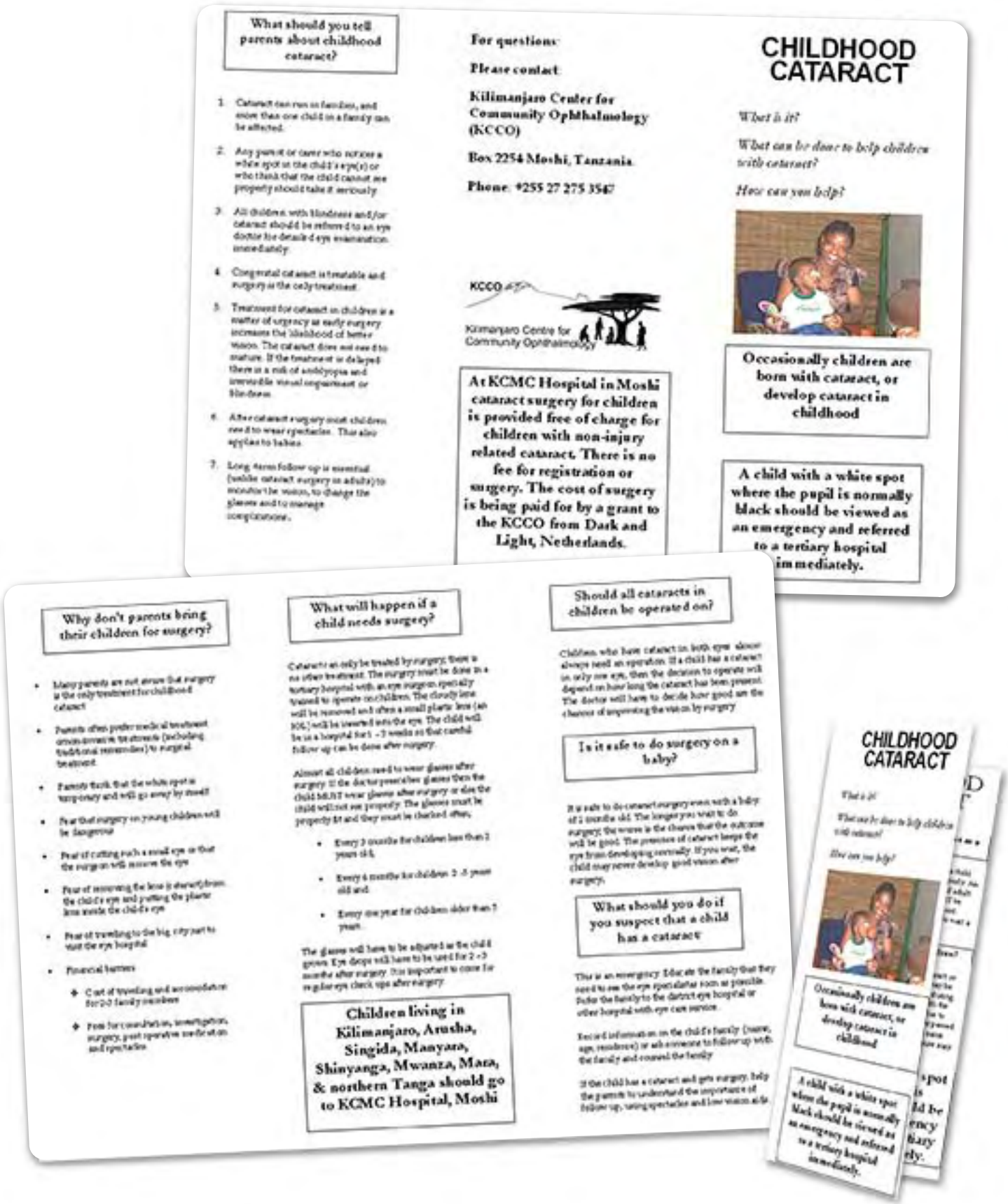
# APPENDIX II Childhood Cataract Brochure for Health Workers



**What should you tell parents about childhood cataract?**

1. Cataract can run in families, and more than one child in a family can be affected.
2. Any parent or carer who notices a white spot in the child's eye(s) or who think that the child cannot see properly should take it seriously.
3. All children with blindness and/or cataract should be referred to an eye doctor for detailed eye examination immediately.
4. Congenital cataract is treatable and surgery is the only treatment.
5. Treatment for cataract in children is a matter of urgency as early surgery increases the likelihood of better vision. The cataract does not need to mature. If the treatment is delayed there is a risk of amblyopia and irreversible visual impairment or blindness.
6. After cataract surgery most children need to wear spectacles. This also applies to babies.
7. Long-term follow up is essential (unlike cataract surgery in adults) to monitor the vision, to change the glasses and to manage complications.

**For questions:**

**Please contact:**

**Kilimanjaro Center for Community Ophthalmology (KCCO)**

**Box 2254 Moshi, Tanzania**

**Phone: +255 27 275 3547**

KCCO

Kilimanjaro Centre for Community Ophthalmology

**At KCMC Hospital in Moshi cataract surgery for children is provided free of charge for children with non-injury related cataract. There is no fee for registration or surgery. The cost of surgery is being paid for by a grant to the KCCO from Dark and Light, Netherlands.**

# CHILDHOOD CATARACT

*What is it?*

*What can be done to help children with cataract?*

*How can you help?*



**Occasionally children are born with cataract, or develop cataract in childhood**

**A child with a white spot where the pupil is normally black should be viewed as an emergency and referred to a tertiary hospital immediately.**

**Why don't parents bring their children for surgery?**

- Many parents are not aware that surgery is the only treatment for childhood cataract
- Parents often prefer medical treatment (medicines, steroids [including traditional remedies]) to surgical treatment
- Parents think that the white spot is temporary and will go away by itself
- Fear that surgery on young children will be dangerous
- Fear of cutting such a small eye or that the surgeon will remove the eye
- Fear of removing the lens (cataract) from the child's eye and putting the plastic lens inside the child's eye
- Fear of travelling to the big city just to visit the eye hospital
- Financial barriers
  - Cost of travelling and accomodation for 2-3 family members
  - Fees for consultation, investigation, surgery, post operative medication and spectacles

**What will happen if a child needs surgery?**

Cataracts can only be treated by surgery; there is no other treatment. The surgery must be done in a tertiary hospital with an eye surgeon specially trained to operate on children. The cloudy lens will be removed and often a small plastic lens (an IOL) will be inserted into the eye. The child will be in a hospital for 1 – 3 weeks so that careful follow up can be done after surgery.

Almost all children need to wear glasses after surgery. If the doctor prescribes glasses then the child MUST wear glasses after surgery or else the child will not see properly. The glasses must be properly fit and they must be checked often.

- Every 3 months for children less than 2 years old.
- Every 6 months for children 2 -5 years old and
- Every one year for children older than 5 years.

The glasses will have to be adjusted as the child grows. Eye drops will have to be used for 2 – 3 months after surgery. It is important to come for regular eye check ups after surgery.

**Children living in Kilimanjaro, Arusha, Singida, Manyara, Shinyanga, Mwanza, Mara, & northern Tanga should go to KCMC Hospital, Moshi**

**Should all cataracts in children be operated on?**

Children who have cataract in both eyes almost always need an operation. If a child has a cataract in only one eye, then the decision to operate will depend on how long the cataract has been present. The doctor will have to decide how good are the chances of improving the vision by surgery.

**Is it safe to do surgery on a baby?**

It is safe to do cataract surgery even with a baby of 2 months old. The longer you wait to do surgery, the worse is the chance that the outcome will be good. The presence of cataract keeps the eye brain developing normally. If you wait, the child may never develop good vision after surgery.

**What should you do if you suspect that a child has a cataract?**

This is an emergency. Educate the family that they need to see the eye specialist as soon as possible. Refer the family to the district eye hospital or other hospital with eye care service.

Record information on the child's family (name, age, residence) or ask someone to follow up with the family and counsel the family.

If the child has a cataract and gets surgery, help the parents to understand the importance of follow up, using spectacles and low vision aids.

CHILDHOOD CATARACT

Occasionally children are born with cataract, or develop cataract in childhood

A child with a white spot where the pupil is normally black should be viewed as an emergency and referred to a tertiary hospital immediately.

# APPENDIX III Childhood Cataract Brochure for Parents

CHILDHOOD CATARACT

*What is it? What can be done to help children with cataract? How you can help?*

What is a cataract?
Cataract is a clouding or opacity of the normally transparent lens inside the eye. Cataracts stop the lens from working properly so sight becomes blurred. A person may have cataract in both eyes or in only one eye. Although most cataracts occur in older adults, it is possible for a baby or young child to have cataract too.

***Cataract in children is curable and service is free of charge.***

For questions

Please contact

Ms. Mary Mosha
Kilimanjaro Centre for Community Ophthalmology (KCCO)
Box 2254 Moshi, Tanzania

Phone: +255 27 275 3547

Mob: +255 744 371 584

**Surgery is available**

**FREE OF CHARGE (through donation from Dark & Light, Netherlands)**

KCCO

Kilimanjaro Centre for Community Ophthalmology

CHILDHOOD CATARACT

**Is a cataract in a child the same as a cataract in an adult?**

No. The effect is much worse because a child has not yet learned to use his eyes properly. An important difference between child and adult cataract, is that cataract in a child MUST be treated urgently in order to ensure a good outcome. In an adult, it is usually OK to wait a few months before treatment.

**What causes cataract in children?**

The child may either be born with cataract or may develop cataract early in life. It may be caused by some disease in the mother during pregnancy or due to some problem with the child's general health. It may also be due to injury to the eye. Sometimes it may be passed to the child from a parent who has the same problem. In many cases, though, no cause may be found.

**A child with a white spot where the pupil is normally black should be viewed as an emergency and referred to a tertiary hospital immediately.**

**How can I tell if a child has cataract?**

A child may be too young to explain about poor vision, but there are some signs you may notice if the child has cataract.

- Family members may notice that the child does not recognize the mother (normally babies recognize mother's face by 2 months of age)
- The cataract may make the black centre of the eye (a look white or grey
- Sometimes the eye with cataract may turn in or out.
- The eye with cataract may show a jiggling movement (nystagmus)
- Sometimes when it involves only one eye, it may be difficult to detect, as the child may be using the good eye too.

A child may have poor vision due to reasons other than cataract. Only eye doctor can determine this.

**What can I do if a child has cataract?**

Cataract can be treated by surgery. There is no other treatment. The surgery must be done in a hospital with an eye surgeon specially trained to operate on children. The cloudy lens will be removed and often a small plastic lens (an IOL) will be inserted into the eye.

**Should all cataracts in children be operated on?**

Children who have cataract in both eyes almost always need an operation. If a child has a cataract in only one eye, then the decision to operate will depend on how long the cataract has been present. The doctor will have to decide how good are the chances of improving the vision by surgery.

**Is it safe to do surgery on a baby? Should I wait until the child is older?**

In hospitals with specially trained doctors, it is safe to do cataract surgery even with a baby of 1 - 2 months old. The longer you wait to do surgery, the worse is the chance that the outcome will be good. The presence of cataract keeps the eye brain developing normally. If you wait, the child may never develop good vision after surgery.

**Can the cataract come back after surgery?**

The cataract won't come back, but sometimes other problems develop. Therefore it is very important that a child who has cataract surgery come back for regular follow up. The child must be examined every few months at first, and will need examination at least once a year for his whole life.

**How long will a child be in hospital for cataract surgery?**

The child will be in hospital for 1 - 2 weeks so that careful follow up can be done after surgery. It is possible for children to go home after 2 days if parents agree to return for follow up within a few days.

**Will a child have to wear glasses after surgery? Will she need to use eye drops?**

Many children need glasses after surgery. If the doctor prescribes glasses then the child MUST wear glasses all the time after surgery or else the child will not see properly. The glasses must be properly fit and they must be checked often, every 3 months for children less than 3 years old, every 6 months for children 3 - 5 years and every year for children older than 5 years. The glasses will have to be adjusted as the child grows. Eye drops will have to be used for 2 - 3 months after surgery.

**Will a child be able to see normally after cataract surgery?**

Many children with cataract in both eyes see better after surgery, but only if it is done very soon after the cataract develops and only if the child wears the proper glasses after surgery. It is important to come for regular eye checks after surgery.

**What is the cost of surgery?**

At KCMC Hospital in Moshi cataract surgery for children is given for free of charge for children with no injury related cataract. There is no fee for registration or surgery. The cost of surgery is being paid for by a grant to the KCCO from Dark and Light, Netherlands

# APPENDIX IV Childhood Cataract Tracking Form

## CHILDHOOD CATARACT TRACKING FORM

HR #

CHILD NAME

PHONE #

| | DATE | COMMENTS | | | |
|---|---|---|---|---|---|
| Presented to eye department | | | | | |
| Surgery<br>Discharge | | | | | |
| Recommended 1st follow up<br>1st follow up | | Refraction done? | | | |
| Recommended 2nd follow up | | Refraction done?<br>(Y) (N) | Spectacles Recommended?<br>(Y) (N) | Spectacles Obtained?<br>(Y) (N) | Low Vision Services Recommended?<br>(Y) (N) |
| Recommended 3rd follow up | | | | | |
| 3rd follow up | | | | | |
| 4th follow up | | | | | |
| 5th follow up | | | | | |
| 6th follow up | | | | | |
| 7th follow up | | | | | |
| 8th follow up | | | | | |
| 9th follow up | | | | | |

We would like to extend our thanks to the photographers who allowed us to use their work, including Joanna Urwin, David deWit, and Lisa Hamm.

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Childhood Cataract in Africa