

**FINAL  
PROJECT REPORT**

*Finding community solutions  
to improve blind and visually impaired children's  
access and acceptance to surgery, optical correction and  
follow up in southern Malawi.*

A2Z Childhood Blindness Eye Health Grants Fund  
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## Table of Contents

<b>1.0</b>	<b>Summary</b> .....	<b>1</b>
<b>2.0</b>	<b>Introduction</b> .....	<b>2</b>
<b>3.0</b>	<b>Study Objectives</b> .....	<b>3</b>
<b>4.0</b>	<b>Study Methods</b> .....	<b>3</b>
4.1	Study design and conceptual framework.....	3
4.2	Study population and sample.....	4
4.3	Data collection methods.....	4
4.4	Data analysis methods.....	5
<b>5.0</b>	<b>Results</b> .....	<b>6</b>
5.1	Outputs and findings.....	6
5.2	In-depth interviews.....	6
5.3	Child eye examination.....	8
5.4	Focus group discussions.....	12
5.5	Main themes arising from initial qualitative data analysis.....	12
5.5.1	Local language understanding of cataract.....	12
5.5.2	Cultural belief on causes and symptoms of Ng'ala (cataract).....	12
5.5.3	Linkage between a cataract and blindness.....	15
5.5.4	Treatment for cataract.....	16
5.5.5	Perceived consequences of untreated child cataract.....	17
5.5.6	Perceived importance of seeking treatment for a childhood cataract.....	18
5.5.7	Perceived satisfaction and benefits of treatment.....	18
5.5.8	Perceived harm to seeking treatment.....	19
5.5.9	Health seeking decisions in a family: encouragement.....	19
5.5.10	Health seeking decisions in a family: discouragement.....	20
5.5.11	De-motivating factors to take action.....	20
5.5.12	Motivating factors to take action.....	20
5.5.13	Future of a blind child.....	20
<b>6.0</b>	<b>Discussion</b> .....	<b>21</b>
6.1	Differences between Doers and Non-doers.....	21
6.2	Gaps in services.....	24
<b>7.0</b>	<b>Conclusion and recommendations</b> .....	<b>24</b>
<b>8.0</b>	<b>Attachments</b> .....	<b>27</b>
	References.....	28
	External and internal determinants.....	29
	Doer/Non-doer questions.....	30
	The "Z" family history of cataract.....	31

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**List of acronyms and abbreviations**

BICO	Blantyre Institute for Community Ophthalmology
COMREC	College of Medicine Research and Ethics Committee
FGD	Focus Group Discussion
HSA	Health Surveillance Assistant
ICEH	International Centre for Eye Health - UK
IDI	In-depth interview
IEF	International Eye Foundation
KI	Key Informant
KIM	Key Informant Method
LSFEH	Lions Sight First Eye Hospital
MK	Malawi Kwacha
MOH	Ministry of Health
NPBC	National Prevention of Blindness Committee in Malawi
OCO	Ophthalmic Clinical Officer
PPI	Progress out of Poverty Index
RA	Research Assistant
WHO	World Health Organization

## 1.0 Summary

Cataract is the most common cause of reversible blindness and visual impairment in children. Children can regain their sight and live independent productive lives if health workers identify them early and they get the recommended surgical, optical and rehabilitative interventions. However, there are challenges to increase the uptake of surgery and improve follow up care.

To improve services for children, the Blantyre Institute for Community Ophthalmology (BICO) and the International Eye Foundation (IEF) conducted a study to understand the social, psychological and physical consequences of blindness in families; to understand why some parents with blind children access services and others do not, and, to explore factors in the family related to decision making that prevent access of health care services. The research compared the clinical social behavior determinants of families that accepted surgery (doers) and families that did not receive surgery (non-doers). The project conducted 62 child eye examinations, 53 in-depth interviews with parents, 21 in-depth interviews with children, and 15 focus group discussions.

- Doer families are slightly better off economically (live in permanent housing and own a radio), have positive attitudes, lived closer to a health facility, and the child's vision loss is less severe (vision loss in one eye), and they are more likely to attend school than the non-doers.
- Quantitative data show a poor understanding among individuals of cataract and blindness in children, and there is a complex array of decisions parents must consider when making decisions to accept surgery for their children.
- There are no obvious reasons cited why parents choose to accept or not accept surgery. These decisions are not dependent on the parent's knowledge. Decisions are complex and involve several family members. The community and the health system may be influential also.
- Intensive counseling is likely to influence parents to accept surgery. Education and counseling modules should be developed and tested based on the results of this study.
- Parents realize that their children will be more independent and less burdensome to the family with even partial sight regained. However, the lack of schools and services for their children remains a barrier to independence and economic well being.
- The clinical examination results on children who received surgery were positive. The number of children with normal vision (VA 6/18 or better) increased from 10 to 18, and the number of the blind (VA 3/60 or worse) was reduced from 15 to 2. Most children, who received surgery and needed eyeglasses, did not have them.
- There are significant gaps in the pediatric services to strengthen such as the rate of referral and follow up examination, provision of eye glasses, and education opportunities.

Cataract programs must ensure that they have strong, linked, and coordinated surgical, community, and rehabilitation interventions. And there must be clear communication channels involving education and counseling. Continued operational research is necessary and should be integral to any childhood program in order to assist evidence-based programs.

## 2.0 Introduction

Cataract and refractive errors are the two most common causes of reversible blindness and visual impairment in children. Children can regain their sight and live fully independent productive lives if they are identified early and receive recommended surgical, optical and rehabilitative interventions. It is estimated that there are 100 cataract blind children in every million child population worldwide.

The Lions Sight First Eye Hospital (LSFEH) located in Blantyre southern Malawi provides pediatric cataract, other surgical, optical, and rehabilitative services for a catchment area of approximately six million people (three million children). Hospital records indicate that only up to 100 children per year are admitted for cataract surgery, representing one third of the total numbers expected. Even more worrying is that among those who attend, up to 50% present late for surgery, usually one year after the problem has been noted, and a third do not come back for follow up after surgery despite providing the family other resources to defray transportation costs. Both late presentation to the hospital and poor post-operative follow-up are associated with complications, which compromises visual recovery and perpetuates disability among children.

Since 2008, the Blantyre Institute for Community Ophthalmology (BICO), located at the LSFEH has conducted community research to compare different methods of identifying children from the community (using trained volunteers versus using health workers). This research has discovered that despite children being identified in the community and the parents promising that they will come to the hospital, at least a third of such children have not attended the hospital three months after being identified.

Several reasons are proposed for the delays and non-attendance. These include poor communication between the health providers, families and communities; parents are not aware that treatment for cataract is available; the referral process is complicated and not clearly understood; parents lack the time and money to go to the hospital; and poor (perceived and actual) outcomes of surgery reinforces fear associated with surgery.

Some of the solutions BICO has attempted to increase the uptake of services for children has involved the Key Informant Method (KIM) and interventions to overcome barriers such as “lack of knowledge” and “transportation” by providing information and assisting parents and children with transportation refunds. Although these interventions have increased the number of children coming for post-surgery follow up examinations, it has not increased the number of children that undergo surgery. These approaches highlight the complexity of reasons for non-attendance suggesting that providing information and transport refunds alone are not sufficient solutions to increase the number of children accepting surgery, and that operational research should be undertaken to identify other deeply rooted reasons in order to create a comprehensive solution.

### 3.0 Study Objectives

To examine the demographic and social cultural factors that impedes families of cataract blind children from attending services.

1. To understand the social, psychological and physical consequences of blindness in children, and their families.
2. To understand why some families with blind children access services and others do not.
3. To explore factors in the family related to decision making and factors in the community that prevents people from accessing health care services.
4. Use research findings to redesign community interventions to increase uptake of services for blind and visually impaired children.

### 4.0 Study Methods

#### 4.1 Study design and conceptual framework

This operational research employed a descriptive study methodology. Qualitative data collection methods, focus group discussions and in-depth interviews, were used to collect data from the respondents. The aim was to generate knowledge through comparison of "Doers" - families with blind children from the same communities who have attended services with "Non-doers" - families with blind children from the same communities who have not attended services. Individual family sociocultural and economic characteristics and other qualitative data on family knowledge, perceptions, and beliefs were recorded and analyzed.

The critical behavior examined was whether a family with a child blind from cataract acted on the advice of the health worker and received cataract surgery at the LSFEH. A conceptual framework of behavior change theory was constructed examining internal and external determinants of behavior.

The external behavior determinants, the forces outside of the family and child that affect the behavior, examined were:

- Skills - do parents have the skills and ability to act on the referral advice, e.g., schedule to leave home, have the resources needed to support travel etc;
- Access - what is the location and distance from home to the health center and hospital that may pose a barrier to access;
- Cultural belief - what families and communities believe they can do to alleviate this problem;
- Consequences - how do the parents understand the benefits of, or lack of benefits, or harm if the child receives surgery.

The internal behavior determinants, the forces internal to the family and child that affect how the decision maker thinks and feels about the behavior, examined were:

- Self-efficacy - do the parents think they can or can't act on the referral advice;
- Perceived social norms - do the parents and other family members close to the mother think she should act on the referral advice;
- Perceived consequences - how do the parents appreciate the positive or negative; advantages or disadvantages of the surgery;

- Knowledge and attitudes - how familiar are the parents of eye disease, impairment and disability, and what are their regular health seeking behaviors;
- Perceived risk - does the family think there are risks to the child of accepting or not accepting surgery.

The questions developed for interviews and FGD revolve around three core themes:

1. What are the advantages and disadvantages of accepting, acting on referral advice and receiving the surgery?
2. What would make it easier or more difficult to act upon the referral advice and get the surgery?
3. Who approves and supports or disapproves or inhibits the decision to accept, act on the referral guidelines and undergo surgery?

By including questions that explore external and internal behavioral determinants, the project team gained additional information in which to understand the difficult decisions families make for their children.

#### 4.2 Study population and sample

The project was undertaken in Zomba, Mangochi and Balaka districts in southern Malawi with a population of 1.5 million (630,000 children). A childhood blindness study was conducted in these districts between 2008 and 2010 that resulted in a list of all blind and visually impaired children. The research team used this community research database of children, and another hospital database of 200 children that received cataract surgery at the LSFEH during the same period. Children appearing in both databases were enumerated as Doers whereas children appearing in the community database but not the hospital database were enumerated as Non-Doers.

At the start, the project hired full time research assistants who first conducted an audit of all blind children from both the databases. The research was conducted between January 2011 and June 2011 in Zomba, Mangochi and Balaka districts in the south-eastern region of Malawi. Before recruiting participants, the project team conducted consultative meetings with key stakeholders that included community leaders and government health workers to discuss and agree on the research methodology and data collection system. All of the study participants were briefed about the research and administered an informed consent agreement following government research policies.

#### 4.3 Data collection methods

The questionnaires and the FGD formats were designed and tested. The project planned 43 in-depth interviews (IDI); 20 Focus Group Discussions (FGDs) and 43 post-surgery eye examinations on children who received cataract surgery. The assessment instruments used were:

1. Focus Group Discussions with families of selected Doers/Non-Doers.
2. In-depth interview questionnaires for parents of children.
3. In-depth interview questionnaires for selected older children (Doers/Non-Doers).
4. Eye examination questionnaire of all children using the “WHO” standardized protocol.
5. Follow up questionnaire for children who received a followed up clinical investigation more than 2 times after their surgery.
6. Case studies of families who were identified as Doers and Non-Doers.



All field work was completed with two teams of two research assistants (RA) and one Ophthalmic Clinical Officer (OCO). Interview guides were developed and administered in Chichewa, the local language. All Focus Group Discussions and in-depth interviews took place in a private location. All information obtained in this research was kept strictly confidential to the extent legally possible. Each participant was assigned an identification code, for instance, P1 for Participant 1, to avoid collecting names. Individual responses were represented by the identification codes. The candidate identification codes were linked to the data generated from focus groups and in-depth interviews. The participants in the focus group discussions and the in-depth interviews were asked to keep the information confidential. A digital voice recorder was used to record conversations and then the recordings were transcribed verbatim into Chichewa and translated into English as soon as possible following the interviews. All data were entered into a computer. Both Chichewa and English transcripts were kept as backup copies. Audio recordings were kept for the entire period of the study, in case any material on the transcripts needed to be compared against the original recording. All of the original transcriptions and tapes were stored in the computer, and the backup copies were locked in the Principal Investigator's filing cabinet. The project team obtained ethical approval to conduct the study from the College of Medicine Research and Ethics Committee (COMREC). The team informed the district health authorities for their approval to proceed. The participants gave their informed consent orally prior to the interviews.

#### 4.4 Data analysis methods

Quantitative data from the In-depth Interviews and the clinical examinations were entered in Epidata, imported and analyzed using STATA 10. Two social scientists (anthropologists) from the College of Medicine were contracted to analyze the qualitative data using grounded theory methods and thematic analysis. The transcripts were studied to determine themes. The themes were coded and the findings compared. If there were any discrepancies found between the interpretations, the material was reviewed in a meeting. A report was produced using direct quotations from the participants. At the completion of the project, the research team met to discuss the results of the quantitative and qualitative findings.

## 5.0 Results

### 5.1 Outputs and findings

The project proposal planned 43 IDIs, 20 FDG's and 43 eye examinations. During the design and work plan phase, a greater number of interviews were scheduled since it was felt that more responses and examinations could be completed, and the additional information would support more families. Tables 1 and 2 show the number of planned and completed interviews, Focus Discussion Groups, child post-cataract surgery clinical examinations and follow up exams by those identified as a Doer and Non-doe.

Table 1 - Planned outputs

	<i>No. Planned</i>	<i>No. Conducted</i>	<i>No. Complete</i>
IDI - Parents	73	53	73%
IDI - Children	27	21	78%
FGD - Community	18	15	83%
Child - Eye Examination	77	62	81%
Child - Follow up post surgery	11	11	100%
Case Studies Families	4	4	100%

Table 2 - Planned outputs by Doer and Non-doe

	<i>No. Doer</i>	<i>No. Non-doe</i>	<i>No. Total</i>
IDI - Parents	37	16	53
IDI - Children	15	6	21
FGD - Community	9	6	15
Child - Eye examination	39	23	62
Child - Follow up post surgery	11	0	11
Case Study Families	2	2	4

### 5.2 In-depth interviews

Fifty-two In-depth Interviews of families were completed to identify the socioeconomic characteristics that may affect their access to eye care services. In summary, Non-Doers are poorer and live further from the nearest health center. Non-Doers are less educated, have less income, and live in less permanent homes than the Doers.

Table 3 - Mothers' education level

	<i>No. Doer</i>	<i>No. Non-Doer</i>	<i>No. Total</i>
Not educated	16	14	30
Educated	23	9	32
<b>Total</b>	39	23	62

Table 4 - Sample of characteristics between Doers and Non-Doers

	Mean*		
	Doers	Non-Doers	P value
Malawi Poverty Level Index	32	24	0.13
Distance from village to health center*	2.4	5.5	0.0098
Distance from health center to district hospital*	25.8	27	0.92
<b>Distance from district hospital to tertiary hospital*</b>	120.8	106.8	0.5

Non-Doers were more likely to come from twice the distance from their village to a health centre than Doers ( $P=0.0098$ ). The Malawi Poverty Index is derived from the Grameen Foundation Progress out of Poverty Index (PPI) for Malawi. The PPI is a tool for micro-finance programs and consists of ten questions on household size, house construction, water source, cooking fuel, lighting, and household ownership of furniture, transportation, and electronics. The scores are converted on a scale of 0 - 100 that are associated with a likely poverty level. Although both the Doers and the Non-doers are poor by any standard, the Non-doers are poorer. According to the PPI index, the Non-doer score of 24 corresponds to 63.9% of the families living below the National Poverty Line and 85.6% living on less than \$1.25 per day (2005 PPP). In comparison, the Doers score of 32 corresponding to 39.4% of the National Poverty Line and 69% living on less than \$1.25 per day (2005 PPP).<sup>1</sup>

Table 5 - Source of income

	<i>No. Doer</i>	<i>%</i>	<i>No. Non-doer</i>	<i>%</i>	<i>Total</i>
Peasant farmer*	18	46%	15	79%	32
Small scale business	10	26%	4	21%	14
Employed manual labor	4	10%	0	0%	4
Employed skilled carpentry, tinsmith etc	7	18%	0	0%	7
<b>Total</b>	39	100%	19	100%	58
P=0.048*					

Non-Doers were more likely to be peasant (subsistence) farmers than Doers.

Table 6 - House construction

	<i>No. Doer</i>	<i>%</i>	<i>No. Non-doer</i>	<i>%</i>	<i>Total</i>
Mud bricks with glass thatched*	9	23%	15	79%	24
Burnt bricks with glass thatched	15	38%	4	21%	19
Burnt bricks with metal sheets	15	38%	0	0%	15
<b>Total</b>	39	100%	19	100%	58
P<0.001*					

<sup>1</sup> The PPI questionnaire was made part of the small survey sample size and could not be administered to the recommended methodology sample size of 200 to 800 people.

Non-doers were more likely to live in houses made with mud bricks and a roof of grass thatch (P=0.001).

### 5.3 Child eye examination

An Ophthalmic Clinical Officer conducted a basic eye exam on 62 children - 39 children that who went to the hospital for cataract surgery (Doer) and 23 children that did not undergo surgery (Non-doer) - to describe the quality of the cataract surgery and contrast vision problems between both groups. The rationale for these examinations was to determine whether a poor visual outcome contributes to dissatisfaction in the population and negative attitudes towards the surgical services. An Ophthalmic Clinical Officer conducted the examinations using a standard protocol. Among the 39 Doers, five children came to the hospital for treatment but did not get cataract surgery due to medical complications.

Table 7- Eye examinations completed by sex

	<i>No. Doer</i>	<i>%</i>	<i>No. Non-doer</i>	<i>%</i>	<i>Total</i>	<i>%</i>
Male	22	56%	14	61%	36	58%
Female	17	44%	9	39%	26	42%
<b>Total</b>	39	100%	23	100%	62	100%

There were more boys than girls examined, but the difference was not statistically significant (P=0.731).

Table 8 - Age of child at time of evaluation

	<i>Age &lt; 6 years</i>	<i>Age 6-10 years</i>	<i>Age ≥ 11 years</i>	<i>Total</i>
Zomba	8	9	19	36
Balaka	2	4	1	7
Mangochi	2	10	7	19
<b>Total</b>	12 (19.3%)	23 (37%)	27 (43.5%)	62 (100%)

The mean age of children examined was 9.5 years; 9 for boys and 10 for girls. Only 19.3% of the children examined fell in the younger age bracket. In Tables 9 and 10, the presenting and corrected visual acuity is shown for all of the children examined to determine the uncorrected refractive error.

Table 9 - Presenting VA (uncorrected) Doer and Non-doer

	<i>No. Doer</i>	<i>%</i>	<i>No. Non-doer</i>	<i>%</i>	<i>Total</i>	<i>%</i>
Normal	22	56%	6	26%	28	45%
Visual impaired	6	15%	6	26%	12	19%
Severely visually impaired	8	21%	1	4%	9	15%
Blind*	3	8%	10	43%	13	21%
<b>Total</b>	39	100%	23	100%	62	100%
<b>P value 0.002*</b>						

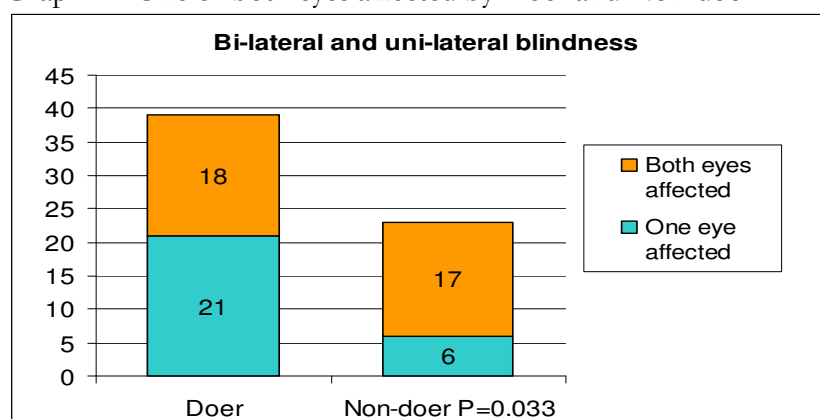
Table 10 - Corrected VA Doer and Non-doer

	<i>No.</i> <i>Doer</i>	<i>%</i>	<i>No.</i> <i>Non-doer</i>	<i>%</i>	<i>Total</i>	<i>%</i>
Normal	26	67%	7	30%	33	31%
Visual impaired	6	15%	5	22%	11	32%
Severely visually impaired	4	10%	1	4%	5	8%
Blind*	3	8%	10	43%	13	21%
<b>Total</b>	<b>39</b>	<b>100%</b>	<b>23</b>	<b>100%</b>	<b>62</b>	<b>100%</b>

**P value 0.004\***

The 23 Non-doers were 3.3 times more likely to have both eyes affected (VA 6/60 or worse vision), compared to the 39 Doers.

Graph 1 - One or both eyes affected by Doer and Non-doer



The Ophthalmic Clinical Officer reexamined the children who received cataract surgery prior to the start of the study to determine whether there was a change in their vision after surgery. "Normal" VA refers to children who had cataract in one eye while the other eye was normal, and the child was otherwise normal.

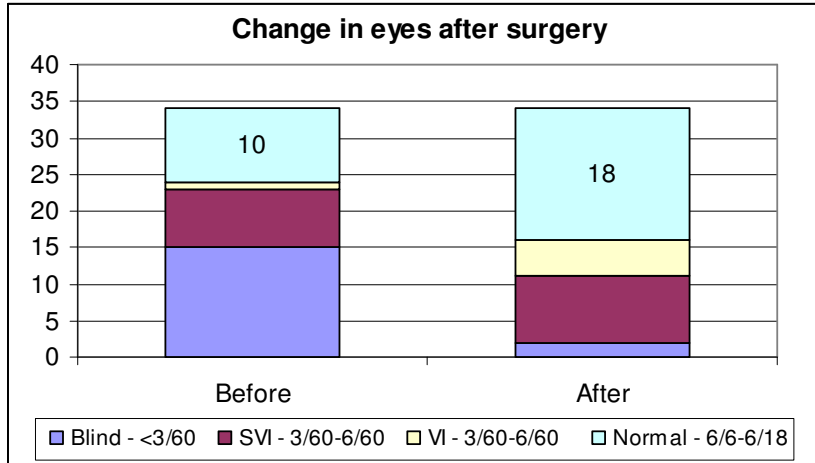
Table 11 - Presenting visual acuity (VA) before and after surgery

<i>VA (WHO classification)</i>	<i>Before surgery</i>	<i>%</i>	<i>After surgery</i>	<i>%</i>
Normal	10	29%	18	53%
Visual impaired	1	3%	5	15%
Severely visually impaired	8	24%	9	26%
Blind*	15	44%	2	6%
<b>Total</b>	<b>34</b>	<b>100%</b>	<b>34</b>	<b>100%</b>

Overall, children's vision improved in almost all categories. While one-third of the children were classified as Normal before surgery more than half of the children obtained full visual recovery after their surgery. The majority of children that remained with either visual impairment or severe VI had posterior capsule opacification. However, the number of blind children was reduced dramatically from 15 to 2. The cause of blindness in the remaining children was to bilateral optic atrophy, extremely high myopia, and nystagmus and cerebral palsy. Overall, it is encouraging that cataract

surgery in children is associated with moderate to good visual recovery, even in low resource settings such as Malawi. Presumably, if all of these children receive corrective eye glasses their vision would improve further.

Graph 2 - Change in eyes before and after cataract surgery

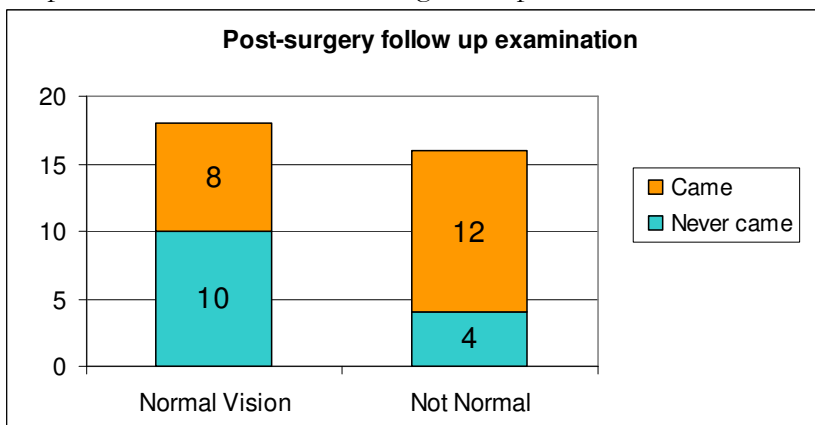


Among the children who received surgery, 14 (41%) never returned for a follow up evaluation and 20 (59%) came for one or more times indicating the need to improve this service.

Table 12 - Children returning for post-cataract surgery follow-up examination

	<i>Normal</i>	<i>VI</i>	<i>SVI</i>	<i>Blind</i>	<b>Total</b>
Never came	10	0	3	1	14
Came once	7	2	2	2	13
Came =>2 times	1	4	2	0	7
<b>Total</b>	<b>18</b>	<b>6</b>	<b>7</b>	<b>3</b>	<b>34</b>

Graph 2 - Number times returning to hospital



Only two (6%) of the 34 children were wearing eye glasses and no child had a low vision device. Following the examination, the families were counseled for further actions (Table 12). The OCO identified an additional 20 children, all Doers, which would benefit from eye glasses and were

advised to go to the hospital for refraction. The 23 advised for cataract surgery are the Non-doers. This illustrates a gap in follow up services that the hospital can tackle directly.

Table 13 - Actions taken

	<b>No.</b>	<b>%</b>
Counseled	12	19%
Cataract surgery	23	37%
Refraction	20	32%
Other surgery	1	2%
Investigation	6	10%
<b>Total</b>	<b>62</b>	<b>100%</b>

The children that received surgeries were more likely to attend school (67%) compared to only 33% of those who did not have surgery. Although the total number of children attending school from both groups was 63%, this percentage is still low compared to the national average of 85%. Among the 18 children not attending school, the majority (94%) had both eyes affected. But there was no difference between Doer and Non-doeer groups.

Table 14 - School attendance Doer and Non-doeer

	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>Total</b>	<b>%</b>
	<b>Doer</b>		<b>Non-doeer</b>			
In school	20	67%	10	33%	30	63%
Not in school	8	44%	10	56%	18	38%
<b>Total</b>	<b>28</b>	<b>58%</b>	<b>20</b>	<b>42%</b>	<b>48</b>	<b>100%</b>

A positive unintended consequence of the study was the decision by 11 Non-doeer families who accepted treatment for their children after being interviewed and receiving additional counseling.

The table 15 - Unintended consequences

	<b>Total</b>	<b>Total converted</b>	<b>%</b>
	<b>Non-Doers</b>	<b>into Doer</b>	
Zomba	15	10	67%
Mangochi	8	1	13%
<b>Total</b>	<b>23</b>	<b>11</b>	<b>48%</b>

Although the project team was careful to minimize bias by administering the questionnaire and conducting the clinical examination according to the study protocol, the intervention process itself motivated these families. In these cases, the project team did not review the specific factors that led to acceptance of surgery, although an observational effect may have contributed to the family decisions. This is not surprising given the intensity of the interview effort. This unintended consequence also suggests that a comprehensive pediatric program will benefit by including extensive counseling to improve the identification, referral and acceptance of surgery.

## 5.4 Focus group discussions

The project team conducted 15 Focus Group Discussions in the target communities. The village locations for the FGDs were divided between communities where a family with a child accepted surgery and where a family did not. A total of 9 and 6 FGDs were held in Doer and Non-doer communities, respectively. The purpose of the FGDs was to generate additional qualitative information on group members' attitudes, beliefs, and customs that contribute to acceptance of cataract surgery. A total of 96 people participated in these interviews. In the following discussion Doer and Non-doer refer to the FGDs.

Table 16 - Characteristics of FGD participants

		<i>No.</i>	%
Gender	Male	44	46%
	Female	52	54%
Education level	None	21	22%
	Primary	47	49%
	Secondary	28	29%
<b>Total</b>		96	100%

## 5.5 Main themes arising from initial qualitative data analysis

### 5.5.1 Local language understanding of cataract

Both the Doer and Non-doer FGD groups were shown a photograph of a child with a cataract. Both groups identified the photographs as "ng'ala" in Chichewa, the local language. Other FGD participants, especially among the Non-Doers confused the photo as "ana m'maso," literally a painful wound in the eye or cornea scarring. The following quotations from the participants confirm the correct recognition of a cataract or "mwana m'maso."<sup>2</sup>

"It's a cataract." (FGD 7, Non-Doer, All.)

"We call this illness a cataract." (FGD 6, Non-Doer, All.)

"Cataract." (FGD 4, Non-doer, All.)

"We only say it's a cataract." (FGD 3, Doer, All.)

"It's a cataract." (FGD 10, Non-doer, All.)

"We call it a cataract." (Chana in Yao and Ng'ala in Chichewa) – (FGD 11, Doer, All.)

The quotation shows confusion: "It's mwana m'maso." (painful wound in the eye) (FGD 10, Non-doer, All.)

### 5.5.2 Cultural belief on causes and symptoms of Ng'ala (cataract)

<sup>2</sup> "All" refers to all participants responding and "P" refers to the candidate's assigned number in the FGD. The qualitative analysis was conducted by social scientists from the College of Medicine.



Both Doers and Non-doers identified similar causes and symptoms of ng'ala. Table 16 below, describes these symptoms and causes.

Table 16 - Causes and symptoms of Ng'ala

Interpretation	FGD Quotation
<b>Cause</b>	
Born with weak veins in the eyes. The weak veins may precipitate the onset of ng'ala. However, participants did not explain further the cause of the "weak veins" in the eye or how this causes cataracts.	"I can explain that this disease comes because you can be born with week veins in your eyes so diseases find advantage on that." (FGD 3, Doers, P15.)
A wound in the eye which may be caused by a prick of a stick; or sand/dust/or sparks which may enter the eye during welding. Or a wound in the eye, which may in the long run leave a scar, may be a cause of cataract.	<p>"It might be that a person had an accident of the eye and that wound grows and it becomes a scar in the eye." (FGD 3, Doers, P15.)</p> <p>"I want to add this disease can come if you do electric job, like welding, that electricity can destroy your eyes." (FGD 3, Doers, P15.)</p> <p>"A cataract comes when children are playing and some dust enters their eyes or even a piece of wood so because of this a cataract can develop." (FGD 4, Non-Doer, P21.)</p> <p>"Sometimes the things that children play with like "tidzitsotso" may enter in the eyes or any other objects they use when playing in their groups or even hurting each other in the eyes so if that child doesn't get treatment fast, then the eye can develop a cataract as you know that sand or any "tidzitsotso" can destroy the eyes of the children." (FGD5, Doer, P5.)</p>
An eye infection which causes a "sandy feeling" in the eyes.	<p>"Just the way they have said it, when you have eye disease you fell like sand in your eyes it makes you to stop seeing." (FGD 3, Doer, P18.)</p> <p>"The illness may start due to eye infections." (FGD 6, Non-doer, P11.)</p> <p>"What happens it that the eyes itch and they become red after that a whitish thing develops." (FGD 14, Non-doer, P5.)</p>
Application of herbal medicine in the eye when a child has an infection. When afflicted with an eye infection, some people seek remedies from traditional healers. The traditional herbs given to apply in the eyes	"It happens that you have an eye disease you end up going to a traditional doctor o be treated not knowing that you will destroy your eyes, due to the trees they will use you will have problems with your eyes, instead of going to hospital." (FGD 3, Doer,

<p>may cause damage.</p>	<p>P20.)</p> <p>"A cataract starts when a child has eye disease and you took him to a traditional doctor, when you receive traditional medicine and you put in your child's eye a cataract can also develop." (FGD 4, Non-doer, P24.)</p> <p>"What causes is that when the child has eye disease and you use traditional medicine and tablets and you put them in the child eye. When the child is born it grows and becomes in-born disease." (FGD 10, Non-doer, P4.)</p> <p>"They become like that because may be you use traditional medicine and a cataract develops." (FGD 13, Doer, P1.)</p>
<p>Unhygienic practices; germs may enter the eyes and cause cataracts.</p>	<p>"This disease can come if you are not clean with your eyes, germs can enter your eyes." (FGD 3, Doer, P15.)</p>
<p>Wearing contact lenses may cause eye disease.</p>	<p>"Some beliefs you are not supposed to wear any glasses, you can cause eye disease." (FGD3, Doer, P19.)</p>
<p>An STI, "chindoko" (syphilis) acquired by child at birth may cause an eye infection which may cause cataracts if untreated.</p>	<p>"Some bacteria cause cataract, other eye disease can be passed on and when a woman is pregnant and has got sexually transmitted disease like syphilis and that disease it's easy for a child to get and when the child is born you find out that he/she has eye problem." (FGD 4, Non-doer, P23.)</p> <p>"I am agreeing with what my friends have said, that this illness may come if one has ever had sexually transmitted infections. The ... it happens that the child has born already with the condition we say its eye cataract." (FGD 7, Non-doer, P6.)</p> <p>"I heard that when a woman has become pregnant and when giving birth with an infection like gonorrhoea then the born child may have such eye condition." (looking at the child cataract pictures.) (FGD 5, Doer, P2.)</p>
<p>Measles can also cause a cataract. Having sexual intercourse with a woman</p>	<p>"When a child is sick from measles, the sores develop in the eyes. Some of them apply traditional</p>

who is about to deliver.	treatment to the eyes, then, that traditional treatment causes a cataract.” (FGD 5, Doer, P5.)
<b>Symptoms/ Presentation</b>	
There seems to be "nkhungu" (fog) in the eye. As a result of the "fog", a person cannot see properly.	"Like there is fog in the eyes, and one cannot see." (FGD 3, Doer, P16.) "The eyes itch and a whitish thing develops in the eyes." (FGD 11, Doer, P4.)
“Ana” appears and closes /engulfs that which enables one to see. "Ana" here refers to whitish “spots” which appear on the eye ball. Gradually these enlarge, gradually encroaching and engulfing the iris, thus impeding vision.	“Ana hides the thing which makes you to see with that you cannot see.” (FGD 3, Doer, P17.)

It is clear that both Doers and Non-doers have a poor understanding of the causes and symptoms of cataract and often confuse cataract with other conditions such as cornea scarring. Some of the inaccurate causes of ng’ala cited above, seem to be entrenched in the local cultural belief and practice framework. For example, belief in traditional medicine and unsanitary practices were some of the cultural beliefs mentioned. Some participants believe that having sex just before child birth can create a cataract in the child's eyes. Some participants believe that semen can attach to the eyes of the fetus and during delivery it appears on the eyes of the baby. Thus one participant stated:

"There are some beliefs that make a child to have cataract for example when a mother is pregnant and the days are due and she has slept with the husband that can also cause the child to have cataract." (FGD 4, Non-doer, P21.)

Other participants believe that a cataract can be inherited from a parent or relative:

“Or we should say that it’s inherited from parents.” (FGD 6, Non-doer, P9.)

“The other thing that causes a cataract can be “chibadwa” maybe inherited from parents.” (FGD 6, Non-doer, P8.)

Some participants also believe that when an expectant mother eats too much hot pepper, her child might be born with an eye complication. They also believe that when an expectant mother eats a lot of tomatoes the child to be born will have red eyes due to tomato consumption. In this case, they explained that the remedy for such a cause is to apply tomato leaves to the affected eye.

### 5.5.3 Linkage between a cataract and blindness

Some participants observed that ng’ala is a cause of blindness.

"It’s true because cataract when has covered on the thing which helps you to see you end up being blind." (FGD 3, Doer, P15.)

Others observed that ng’ala cannot cause blindness.

“The two are not the same. A person with ng’ala has partial sight. A blind person does not have any sight.”

The difference between the two, is that when a person is blind, they do not have any vision while those with ng’ala “can see, but cannot see far.” The "whitish thing" that covers the iris "make one not see far, they see 'mbuu.' grayish things."

"Cataract cannot make one to be blind because a blind person doesn’t see anything while the one with cataract can see but not at a distance, can see things that are near or cannot see." (FGD3, Doer, P20.)

Others observed that the two are one and the same thing

In summary, most of the participants observed that a cataract affects one eye while blindness affects both eyes. They also observed that a cataract appears on the pupil of the eye while blindness attacks the entire eye. They also noted that a person with a cataract often has some vision while a blind person has very little or no vision. The majority of the participants agreed that a cataract can cause blindness if it is left untreated. One participant said:

“It’s true that if we ignore the child so the condition turns into blindness and his/her future is finished right there.” (FGD 6, Non-doer, P10.)

#### 5.5.4 Treatment for cataract

Some participants observed that ng’ala can be treated by going to the hospital. However, some respondents did not indicate exactly how cataracts can be cured. The idea that ng’ala can be cured at the hospital stemmed from witnessing children who had cataracts and received surgery.

"The ng’ala which can be treated/cured is the one where it is presented early." (FGD 11, Doer, P8.)

"A cataract can be treated if the people have seen that condition and have rushed to the hospital. It’s possible to treat a cataract because the medical staff has skills they use when treating a cataract with the education they acquired." (FGD 7, Non-doer, P3.)

"I believe because my child had the same problem she was unable to see because of cataract in both eyes and now she is okay and I believe that if you can go to hospital you will be treated." (FGD 3, Doer, P17.)

"Yes, it can be cured if you can go to the hospital." (FGD 13, Doer, P1.)

"It’s true that a cataract can be treated but when you have gone to the hospital and meet the doctors." (FGD 9, Doer, P4.)

Some participants mentioned that through "kupala," the surgery, a person with ng’ala can regain sight again:

"I believe because my child had the same problem she was unable to see because of cataract both eyes and now she is okay and I believe that if you can go to hospital you will be treated." (FGD 3, Doer, P17.)

"It's true that can be treated if you go to hospital they will operate what makes people not to see and they can see properly." (FGD 3, Doer, P15.)

However, they also observed that there are rumors in the area that link cataract surgery with blindness and urged each other to dispel such rumors in their communities. They noted that it is very important for parents of the affected child to hurry her/him to the hospital whenever they realize that their child has a cataract. Participants said:

"The big thing and what we can encourage each other is that when we have seen these signs we should rush in applying the traditional medicine to the child. The most important thing is rushing to the hospital with the child because if we don't do that then that illness will get established, and it's for child to get healed when it has established." (FGD 5, P3).

"A cataract can be treated when you rush to hospital if this condition occurs." (FGD 7, Non-doer, P4).

There were also some participants who admitted that they did not know that a cataract could be treated at a health facility.

#### 5.5.5 Perceived consequences of untreated child cataract

The majority of participants noted that if a child does not get cataract treatment at a hospital, the child will never see and they will be "ozuzika" or "in trouble" all their life. By not taking the child with ng'ala to a hospital, the guardian will have trouble taking care of the child. To avoid this, participants urged parents with such children to go to the hospital. Participants noted that the outcome of untreated ng'ala is twofold: first, the child will lose sight "mwana sangawone" and as a result he/she cannot do any work. Second, the fact that the child cannot work or taking care of him/herself, places the burden of responsibility on the family to care for the child. Parents will always have to assist the child if he/she wants to go anywhere. Thus, there will be loss of freedom to the guardian.

"The results if you didn't go to hospital first the child cannot see, can't work and can affect the whole family because they will not work they will be busy caring for the child because cannot take care of himself since cannot see." (FGD 3, Doer, P15.)

"The parents are always in problems because you have to take the child by hand and guide her if she wants to go anywhere." (FGD 3, Doer, P20.)

"If the child didn't receive treatment will never see again and will suffer the rest of her life." (FGD 3, Doer, P20.)

To a girl child, the importance of having a cataract is more dangerous because she is exposed to predatory men.

"If the child has a cataract or blindness condition, if she is grown up girl, can meet some fathers who can't control their libido, they can just rape her and transmit today's virus because she has no sight." (FGD 5, Doer, P5.)

They also noted that untreated disease can lead to blindness which is worse than a cataract. Here one participant said:

"The illness on the picture is a cataract so if she/he does not receive treatment then it's obvious that blindness will come. We are selfish when we have sight but if there is blindness the life of the child will be at risk." (FGD 5, Doer, P2.)

#### 5.5.6 Perceived importance of seeking treatment for a childhood cataract

A child who was treated can regain sight. A participant narrated an example of a child who "was not able to see anything before" and was not able to walk on her own, and as a result she was not attending school. However, after the child was treated, she regained partial sight. The result was that she was able to walk on her own to school, to do household chores, such as fetching water from a borehole.

"This woman her child could not go to draw water but now she is doing that alone. I believe that the child is able to see because of the hospital and was been helped now she can see partially because the hospital helped her to arrive at that stage." (FGD 3, Doer, P20.)

"Just to add the boy you have seen first time we saw him they could hold him on the hand but now he walks alone meaning the problem was treated." (FGD 3, Doer, P15.)

"We have Mr. M. at home, they have a child he was blind when they took him to hospital to receive treatment, right now he can see, goes to school, ride bicycle, he does everything and people they don't believe that he could not see." (FGD 3, Doer, P19.)

The age of children who had received treatment in the community ranged from 5 to 15 years. They also observed that blindness is common among adults in their communities, because most of them had untreated cataracts.

#### 5.5.7 Perceived satisfaction and benefits of treatment

Majority of respondents observed that parents of children who sought treatment were generally satisfied at seeing the changes in their children, e.g., ability to work, to see properly, to go to school.

"They are satisfied if they see what the child is doing going to school which means the parents they do believe." (FGD 3, Doer, P20.)

"... the family is happy ... they didn't believe that the child can regain his sight, they were helped and now they are happy that the child is able to see." (FGD 3, Doer, P15.)

If a child with ng'ala is taken to hospital early, the problem can be treated. However, if neglected, the problem increases to the level that it may not be cured in future. If a child is treated, a parent is more able to engage in work, either in the house or in a paying job.

"Just to add with two words when the child has born with eye disease when he grows the disease also grows but when you are young then you go to hospital the disease will be treated without problems." (FGD 3, Doer, P19.)

"It is important because if you will not take the child to hospital the disease will grow but if you go to hospital will be treated and you will be doing your job as parent." (FGD3, Doer, P19.)

#### 5.5.8 Perceived harm to seeking treatment

The majority of participants noted that there is no harm associated with taking a child with ng'ala to the hospital. If the child is unable to see, he/she only stands to gain by going to hospital

"It's not bad, the child needs to go to hospital and is important, if the child cannot see has to see so it's not bad to go to hospital." (P15.)

However, some participants feared that surgery may worsen the condition of children and result in blindness.

#### 5.5.9 Health seeking decisions in a family: encouragement

The majority opinion was that either the husband or the wife decides, through dialogue with the other, on whether to take the child to the hospital. Their motivation is to avoid the burden of caring for a blind child. However, other participants observed that it is usually the mother who initiates and encourages going to the hospital because she is the primary caregiver, while the husband is often away working for the family.

A minority of the respondents mentioned that it is the duty of the husband to decide to take the child to the hospital. Others also observed that mothers are the ones who take the child to the hospital when such decisions are made by the family. Other family relatives apart from the husband and wife may also play a role in decisions to go to the hospital.

"Both a husband and a wife if you see it's a burden from a child you need to agree so that the child should go to hospital if you will not talk to each other concerning the child issue you will just be looking at the child." (FGD 3, Doer, P20.)

"The way I see it it's the mother because while the father is often away, the mother is always at home, so the one who sees the problem it's the mother." (FGD 3, Doer, P15.)

"It's the man who makes an effort for a child to go to hospital in the family if there is a problem it's the man who has to be on the forefront." (FGD 3, Doer, P19.)

"All in the family father and mother make a decision to take the child to the hospital." (FGD 6, Non-doer, P28.)

#### 5.5.10 Health seeking decisions in a family: discouragement

The majority of the participants mentioned that it is usually men who don't promote health seeking behavior. They may ignore the child and use their time to socialize; or they may prefer taking the child to a herbalist first instead of the hospital.

"Those who do this mostly are men, they can go and drink beer forgetting that the child is sick." (FGD 3, Doer, P20.)

"What number 6 is saying it's true, some men they say let's go to a traditional doctor may be he has been bewitched so its men who do not encourage in taking the child to hospital." (FGD 3, Doer, P15.)

#### 5.5.11 De-motivating factors to take action

Other factors that discourage parents from taking their children to the hospital are:

**Fear of surgical procedure:** Many people perceive surgical procedures as a key de-motivator. Surgery was perceived by some as harmful to the eyes, i.e., the procedure will worsen the condition of the eye. Some people think that the procedure will "remove" the eye. People are afraid with the concept of an operation, viewing it as therapeutic, but rather invasive and injurious. So they would rather shun the hospital if told to undergo an operation. Instead, may opt for traditional medicine because surgical procedures are lacking.

**Distance to the hospital:** Many people may need transportation to a health facility. Such specialized referral facilities are few and far from those who need them. Here participants explained that in some cases they lack transportation from their homes to the hospital.

**Other beliefs:** Many parents believe that cataract is hereditary and it cannot be cured at the hospital, or their religious beliefs do not let them to seek treatment at the hospital.

#### 5.5.12 Motivating factors to take action

All participants noted that parents with cataract children need encouragement and emotional support from their fellow community members including government Health Surveillance Assistants (HSA) who work in the communities. They stated that if parents with a cataract child see another child who had a cataract but had gone to the hospital to receive treatment and was able to see, they would be encouraged to take their child to the hospital too.

"My younger sister stays the other side, she was blind and was using glasses but she went to hospital and the problem is no longer there. She has a good job and the blouse I am wearing is hers. Others can get encouragement from this." (FGD 6, Non-doe, P29.)

#### 5.5.13 Future of a blind child

Most participants observed that blind children have no future if they are not educated. According to them, blindness is as good as death if it is not treated and the child is not trained in anything. Participants said:



"A blind child has no future. Blindness is good as being dead, the future of the blind child even the friends who are chatting with, even if you can have a good thing if you cannot see, there is no life and future." (FGD 4, Non-doer, P21.)

"The future of a child with cataract and blindness is difficult because he/she can not go to school and can't see properly, can't read and has to be helped as he/she grows." (FGD 6, Non-doer, P31.)

"The future of this child is difficult because there are few families who might be well to do but for the child who is not seeing, the future is difficult." (FGD 2, Non-doer, P10.)

They also explained that they have heard stories on the radio about blind people who were educated and they are doing well now. Thus two participants observed that:

"We just hear through the radio that there are some blind people who are doing well. They are in offices and even doing business through what they have been trained." (FGD 4, Non-doer, P23.)

"As we know that there is school for the blind, so, we can't differentiate much his future with the people who have sight knowing that what a normal person can learn, a blind person can learn it too because this blind person can be lucky to go to school and get employed afterwards just like a person who can see. It's up to the parents to take him/her to schools where he/she can learn." (FGD 5, Doer, P2.)

## 6.0 Discussion

### 6.1 Differences between Doers and Non-doers

This operational research study was designed to explore why some families undergo surgery for their cataract blind and visually impaired children while others do not. Based on the findings, the project team seeks to develop strategies to increase access and use of the available surgical, optical correction, and follow up services for these children in southern Malawi.

There are important, but minor differences identified between the Doers and the Non-doers. The Non-doers are poorer, less educated, live further from the nearest health center, and their children are more likely to have cataract in both eyes and not attend school than the children of Doer families. Although poverty and education make it difficult for any family to access health services, these families may have less frequent contact with the health services and their lack of knowledge may hinder their ability to benefit from health communication messages. The importance of distance from the home to the health services is also evident from the results. Doers live in villages that are closer to the health centre than Non-Doers. It is possible that being closer to the health centre exposes them to more health promotion messages and being closer to the health center reduces the transportation and opportunity costs associated with care.

It is also not surprising that the health center is considered as the first point of contact with the health system than the district hospital or the tertiary hospital. It is encouraging to see that families will go the health center even if it is distant. However, this exposes a gap in the service delivery

system. The further away the health center is from the district hospital and tertiary hospital, there tends to be less support. This may be particularly the case for eye care as there are few trained eye care professionals, even at the district hospital and none at the health centers.

Although the socio-economic indicators identified are important, the study identified other key but less tangible determinants that influence behavior. The qualitative research provides a greater understanding of what individual families, community members and leaders think and believe about blindness and visual impairment that may influence family decisions to seek care. While it is difficult to summarize these differences, it is useful to understand the context in which families make decisions.

Even though the word "ng'ala" (cataract) is deep-rooted in the Chichewa language, rural people have limited knowledge and accurate understanding of its symptoms, treatment and the relationship with blindness. Cataract is frequently confused with other causes of corneal opacity. This is not surprising because these communities are familiar with the problems of vitamin a deficiency and xerophthalmia in the recent past, and adult cataract through the outreach campaigns that regularly take place in these districts. Regardless, families know when the child has an eye disease or condition that requires treatment, and most agree that children can be treated in the hospital. Also, many families were aware that other children have received treatment with good results and that ignoring the problem may cause greater harm.

It was clear from the interviews and the focus group discussions that families understand that blindness in children is a burden. This may be particularly important for girl children as many perceive that a girl is at greater risk due to the potential of exploitation. A blind child requires greater attention from family members taxing family resources for a lifetime. A child is expected to contribute to household chores and to the economic well being of the parents in the future. Thus, a blind child adds additional burden to a family.

Most of the respondents reported positive attitudes toward treatment for the child at the hospital, and do not think harm will result from surgery even though the visual outcome of the surgery may be less than expected. The decision to accept or refuse surgery is complicated. There were no clear single reasons cited for decisions made one way or the other. In most cases, it appears that the mother initiates the decision but the father often plays a deciding role. In other cases, another family member contributes to the decision, such as an aunt and uncle or grandparent. This fact highlights the importance to determine who the target is for health communication about childhood cataract. And different persons may require different counseling and negotiation tactics.

The clinical examination results on children who received surgery are positive. The vision among the majority of the 34 children improved after their surgery; the number of children with normal vision increased from 10 to 18, and the number of the blind was reduced from 15 to 2. These improvements are notable given the fact that, at the time of surgery, many of these children were older than the age recommended for intervention, and only sixty percent returned for one or more follow up examinations.

In general, families are satisfied if the child recovers some of their sight. Parents realize that even partial sight enables greater independence in everyday life functions. The respondents often referred to the future of the child and especially the importance of education. In Malawi, education is valued highly and families want their child to attend primary school, if not secondary school. An educated

child is more likely to be employed and employment will benefit the whole family. In a related manner, many families also expressed pessimism about the quality of life of a blind or visually impaired child. Even if a child benefits from treatment, the absence of special schools and services for the visually impaired remains a barrier to their child's independence and the family's economic well being. These families know that treatment is part of the solution; but it is only an advantage if the child is provided continued support.

Despite what was learned from the study, there are no striking differences that predict whether a family accepts surgery. To illustrate this, two families with family histories of cataract are contrasted below.

<b>"K" family, Zomba District</b>	<b>"Z" family, Zomba District</b>
<ul style="list-style-type: none"> <li>• Four children, 1 boy and 3 girls; aged 14 years (girl), 11 years (girl), 8 years (girl) 2 years (boy).</li> <li>• Father and 3 children bilateral cataract and the mother and daughter aged 8 do not.</li> <li>• Strict Muslim family; poor; not educated and don't send their children to regular school.</li> <li>• Initially refused interview but agreed after a neighbor intervened. Parents avoided the meeting the next morning and left for their garden work despite knowing our planned visit.</li> <li>• Upon interviewing, the parents believe that nothing can be done about their family's vision problems and don't want to talk further. The parents state that they will never go to hospital under any conditions.</li> </ul>	<ul style="list-style-type: none"> <li>• Five children, 3 boys and 2 daughters (the daughters are now adults and have their own families).</li> <li>• Mother had a cataract while the father does not.</li> <li>• The 3 sons had bilateral cataracts while their 2 daughters do not.</li> <li>• Grandchildren (from the sons) had cataracts while the daughter's children do not.</li> <li>• Strict Muslim family, poor, not educated but they send their children to regular school.</li> <li>• All children of school age go to school.</li> <li>• Parents of children who have had cataract were eager to take their child to the hospital early in their lives (at 6 months).</li> <li>• Parents also came for the post-surgery follow examinations.</li> <li>• Despite having one child with a poor surgical outcome, parents believe their child can benefit from education and believe that a blind/visually impaired child can live a normal life if parents support their children.</li> </ul>

## 6.2 Gaps in services

The research identified gaps in the pediatric services that can be strengthened. An effective pediatric service is based on a range of care that must be in place if services are to be effective and of high quality - patients must be identified in the community and strategies designed to improve referral, access and use of the services; the hospital must provide quality surgery, follow-up examination, corrective eyeglasses, and low vision devices; and affordable rehabilitation and education services must be available to families.

Currently, children in southern Malawi are identified efficiently using the Key Informant Method, but more than half of the children identified are not using the surgical services. This gap in the referral system must be rectified to improve the effectiveness and efficiency of the program. As a result of the project 11 children (48%) in the Non-doer category accepted surgery. This unintended consequence was probably a result of the project team's efforts to interview families to explore their knowledge, attitudes, beliefs, and their perceived ability to act on the advice of the health workers. More importantly, this interaction was intensive and personal in nature. This suggests the need to develop a comprehensive counseling component to the program. A counseling module can be developed based on the interview questions; and can be tested and modified at a low cost be made a part of the Key Informant Method.

Another gap in services identified was the lack of eyeglasses for children after surgery. A total of 20 children would benefit immediately if they had high quality prescription eyeglasses. Presently, there is a full service optical program located in the Lions SightFirst Eye Hospital that is capable of providing high quality pediatric refraction and prescription eyeglasses. Although, there is an additional cost to provide eyeglasses, the quantity required is reasonable and can be supported by the hospital and its donors.

## 7.0 Conclusion and recommendations

There is much we still do not know regarding cataract in children. Many families with children who need services are not accessing services despite attempts to address some of the known barriers such as knowledge and support to families for their transportation costs to the hospital. The operational research has highlighted the complexities involved in understanding behavior and finding solutions to increase acceptance and access to surgical services.

It is evident from the qualitative research that the decision to undertake surgery is not dependent on knowledge. The decisions parents make are complex and involve several family members, and decisions are reinforced further through neighbors, other community members, and the health system. The decision to accept surgery is also likely made in stages. A family may first not understand what cataract is and what can be done at the hospital. A family may have fears to overcome or need approval from family members, or they may be unsure how to prepare themselves to travel to the hospital. For a family to make a decision, they must believe and understand that the benefits outweigh disadvantages.

There are important gaps in the existing pediatric eye care program that planners can fix now without major financial support. The protocols for pediatric eye care can include a negotiation and counseling education module to convince families to accept surgery, and this can be integrated into the Key Informant Method and referral system. A counseling module can also strengthen the

instructions to families to return for their recommended follow-up eye examinations; and all children that require corrective eyeglasses after their surgery can get them from the hospital. Strengthening the entire system will engender positive attitudes towards the services. As the number of children successfully treated increases, and as the services become more convenient and effective, families may perceive that the advantages of treatment outweigh any perceived disadvantages. It is hoped that positive support from the community will tip the balance towards all families accepting treatment.

A more complicated situation is the lack of educational opportunities for visually impaired children. Currently, there are few schools for the blind and most exceed their capacity. The effectiveness of the community-based rehabilitation program needs to be evaluated. As children undergo more surgery, the need to increase the number of rehabilitation and education units is essential to improving the pediatric eye care programmed in Malawi.

The time allocated for this project was very short and was not sufficient to address all of the problems related to childhood blindness. However, the information obtained from this research is valuable and has provided a better understanding of family behavior and possible options to improve services in the immediate and the long term.

Finally, further research is needed to investigate the best use of a counseling module; and how interventions are best coordinated between the hospital and the health centers, and the rehabilitation services available.

### Recommendations

1. A childhood cataract program should have strong surgical, community, and rehabilitation interventions that are linked and well coordinated.
2. Communication - The misunderstanding of the signs, symptoms, cause, and treatment of cataract contributes to the parents' indecision on whether to accept cataract surgery for their children. Families, community leaders, and community-based health workers must have information that is accurate, communicated into simple terms, and provided consistently and frequently. Information should emphasize:
  - a. Some families are at greater risk of cataract than others;
  - b. There are more advantages and benefits of treatment than there are disadvantages of treatment;
  - c. The mother, father, and extended family must talk together to make a decision to seek treatment;
  - d. The sight restored to a child benefits the child and the family intrinsically, socially, and economically;
  - e. There are risks to the child, if a decision for treatment is delayed;
  - f. The family should return to the hospital for the follow up examinations to review progress, get corrective eye glasses, and advice on rehabilitation and education;
  - g. Surgery and corrective eye glasses will help a child in school and prepare for a better future;
  - h. There are many examples of visually impaired people who receive an education and lead productive lives;

- i. The Village Headman and village committees (health, education, development, etc) should be involved in some aspects of reinforcing, encouraging, and enabling the family to make a decision to seek surgery.
3. People and training - The role and responsibility of government workers (health, education, and community development) is to reinforce positive actions of families and communities.
  - a. Train health, education and development workers to understand what to do for blind children in their villages;
  - b. Consider retraining the Key Informants in counseling strategies;
4. Processes - Continue improving the processes to find children, refer, treat, follow up and rehabilitate.
  - a. Develop and test a counseling module that a health worker, teacher, community development assistant, or community member can use to help families make informed decisions;
  - b. In those villages with a blind child, inform the Village Headman and village committees of their responsibilities to enable families to make informed decisions;
  - c. Parents should be given enough time to make their decision. Several counseling sessions may be needed to ensure that parents accept surgery;
  - d. All children who have had surgery should receive follow up reminders (telephone calls, text reminders, home visits) to improve follow-up examination rates;
  - e. All children receiving surgery should be refracted and receive corrective eye glasses, if prescribed;
  - f. Ensure that KIs reach all areas in a district as children from the peripheral areas are most likely not to attend;
  - g. Continue monitoring a cohort of children who have had cataract surgery to demonstrate the long term benefits of cataract surgery on children's lives;
  - h. Standardize criteria, methods, and tools for data collection to ensure valid comparisons are made;
  - i. The Ministry of Health and Education must coordinate to ensure that children who had had cataract surgeries end up in appropriate schools and use the correct form of learning materials (optical and non optical devices).
5. Research - Support evidence based programs with continuing research. Consider researching:
  - a. Who makes the best counselor; health workers, KI, other?
  - b. What is the additional cost to integrate counseling in the KIM?
  - c. Are there more boys than girls with cataract?
  - d. What is the prevalence of inherited cataract in families?

## 8.0 Attachments

References

External and internal determinants

Doer and Non-doer questions

The "Z" family history of cataract

## References

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## External and internal determinants

**EXTERNAL DETERMINANTS.** The forces outside the individual that affect his or her performance of a behavior.

**Skills.** The set of abilities required to perform a particular behavior. Key skills for seeking eye surgery are communication, negotiation, and planning travel.

**Access.** Encompasses the existence of services, their availability to an audience and an audience's comfort in accessing or using a service.

**Policy.** Laws and regulations that affect behaviors and access to a product and services. Policies affecting who can use services and the regulation of services.

**Culture.** The set of history, customs, lifestyles, values and practices within a self-defined group. This may be associated with ethnicity, socio-economic and language groups.

**Actual Consequences.** What actually happens after performing a particular behavior.

**Relationship Status.** Type of relationship as categorized by the family partners and their community. Common categories are short-term/long-term, casual/serious, and monogamous/ multiple partners.

**INTERNAL DETERMINANTS.** The forces inside a person's mind that affect how he or she thinks or feels about a behavior.

**Self-efficacy.** A person's belief that he or she can do a certain behavior (access surgical services for their children).

**Perceived Social Norms.** Perception that people important to an individual think that he or she should do the behavior. Norms have two parts: who matters most to the person on a particular issue, and what he or she perceives those people think he or she should do.

**Perceived Consequences.** What a person thinks will happen, either positive or negative, as a result of performing a behavior.

**Knowledge.** Basic factual information about the eye disease, how to act on advice and recommendations to seek treatment, or where to get services.

**Attitudes.** A wide-ranging category for what a person thinks or feels about a variety of issues. This over-arching category would include self-efficacy, perceived risk and other attitudinal factors.

**Perceived Risk.** A person's perception of how vulnerable they feel (to eye disease).

**Intentions.** What an individual plans or projects he or she will do in the future; commitment to a future act. Future intention to perform a behavior is highly associated with actually performing that behavior.

AED/CORE Group Behave Framework, 2003.

### **Doer/Non-doer questions**

What good things might happen if you \_\_\_\_ (perform the behavior)?

What bad things might happen if you \_\_\_\_ ?

What would make it easier to \_\_\_\_?

What would make it more difficult to \_\_\_\_?

Who approves or supports you when you \_\_\_\_?

Who disapproves or objects you when you \_\_\_\_?

AED/CORE Group Behave Framework, 2003.

## The "Z" family history of cataract

