Exploring community solutions to improve children's access and acceptance to cataract surgery, optical corrections and follow up in Southern Malawi

International Eye Foundation &
Blantyre Institute for Community Ophthalmology
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A2Z Childhood Blindness Program
Partners Meeting, Washington, D.C.
July 25-26, 2011

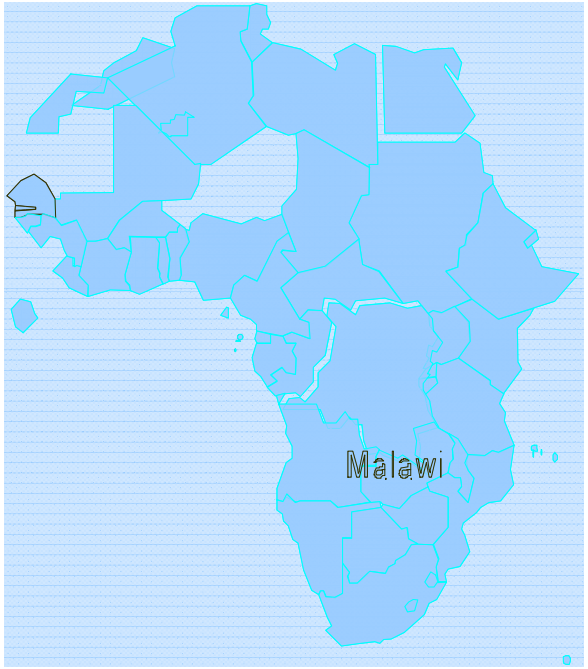
Background

- The most common treatable cause of blindness in children is cataract;
  - delayed presentation is associated with poor outcome.
- Different approaches used to identify blind/VI children in the community
  - Key Informant Method (KIM) evaluated showing success.
- Barriers such as awareness, distance, and transportation traditionally viewed as main obstacles hindering access.
- Despite children being correctly identified and assisted with transportation from the community, still a substantial number do not attend services.
- Is there anything else we do not understand?

Muhit et.al BJO 2007, Mwende et.al BJO 2008

Malawi - Situation

- Malawi is a small country in Southern Africa
  - Bordered by Tanzania, Mozambique and Zambia
  - Densely populated – 13 million inhabitants:
  - 42% less than 15 years (5,460,000)
  - Southern Malawi has approximately 6 million persons
- Prevalence of cataract blindness in children
  - 100 per million population
  - Thus southern Malawi has 600 cataract blind children
- Only 100 cataract patients served at the only paediatric centre in country located at LSFEH in Blantyre.



- Health system is entirely free and transport often provided from the health centre/district hospital to LSFEH. <u>So why the small numbers?</u>
  - Either current prevalence estimate is too high, or
  - Children with cataract are not attending services

Lions Sight First Eye Hospital

Aim & Objectives

Aim:

To explore through quantitative and qualitative methods the demographic, social cultural and behavioral factors that deter families of cataract blind children from attending services when services are available and other common barriers have been addressed.

Objectives:

1. To identify cataract blind who have and have not accessed cataract surgical services.
2. To understand beyond listed reasons why some families with children who are blind do and not access services.
3. To redesign community intervention packages that will increase uptake of services for cataract blind children.

Study Design

- A case control study:
- Generate information through comparison of cases of families with cataract blind children who have attended services (Doers) with control families with cataract blind who have not attended services (Non doers).
- Compare characteristics of children who attend and who did not attend the hospital (behavioral determinants, (age/sex, parent's education, poverty, access, knowledge, perceived risk, perceived social norms, perceived self efficacy, surgical outcome etc).

Methodology & Study Instruments

Database

- Used 2 different database for sampling children from 3 districts in southern Malawi
  - BICO database of community interventions in 3 districts between 2008 & 2009: used to identify children who were identified and referred with cataract.
  - BICO database for hospital records for children who received surgery between 2008-2010: used to extrapolate cases of children who received surgery.

Instruments

- Focus Groups discussions with families of selected Doers/ Non doers.
- In-depth Interviews to parents/guardians of all children
- In-depth interviews to selected older children (Doers/on doers).
- Eye examination questionnaire for all children.
- Follow up questionnaire for children who were followed up more than 2 times after surgical operation.
- Case studies of families of cataract who were classical Doers and Non doers.

Data Analysis

- Qualitative data analysis done by anthropologists using grounded theory technique – these were part of the survey team.
- Quantitative data entered in Epidata, imported and analysed using STATA 10.
- At the end team of researchers had a forum to discuss results and relate quantitative to qualitative findings.

Outputs

Planned Outputs	Planned	Conducted	Coverage
Eye exam children	77	62	81%
IDI parents	73	53	73%
IDI children	27	21	78%
FDG's community	18	15	83%
Children came for follow up	11	11	100%
Case Studies Families	4	4	100%

Proposal outputs – 43 IDI; 20 FDGs; 43 examinations

Cases vs. Controls

Completed	Doer	Non-doer	Total
Eye exam children	39	23	62
IDI parents	37	16	53
IDI children	15	6	21
FDG's community	9	6	15
Children came for follow up	11	0	11
Case Studies Families	2	2	4

IDI Parents

Doer/Non Doer	Comment	P value
Mother education	No difference	0.13
Source of income	Doers likely to have additional source other than farming	0.04
Housing	Doers had slightly better housing (burnt bricks with iron sheets)	0.001
Distance		
Village to PHC	Shorter for Doers	0.01
HC to District	No difference	0.5
District to Tertiary	No difference	0.9
Radio	None of Non doers had a radio	0.03

IDI Parents

Doer/Non Doer	Comment
Local cataract terminology	Confusing with cornea scarring
Cause and symptoms	Not clearly understood between both groups
Perceived risks	Doers more worried about child's education & future
Culture & social belief	Doers don't think it's Gods wish: Non doers indifferent
Decision making	Guided by family members among doers. Non doers: Independent, guided by influential family members

IDI Parents

Themes	Doer	Non Doer
Perceived consequences	"Bright future for the child: As of now he manages to read and write. The surgery has helped us" mother	"The child will never be able to go to school because a blind child can not learn." Mother
Encouragement	Provision of transport. Visiting them in the village Worsening of the child's condition	None
Discouragement	Some family members discouraging them to go	Transportation means. "Am intolerable with the smell of car fuels. I vomit when a board a vehicle." father
Attitude	Happy that transport was provided	Disappointed
Expectations	They are expecting a bright future for the child because vision is restored.	"We shouldn't be cheated; he will be in problems the rest of his life." Mother

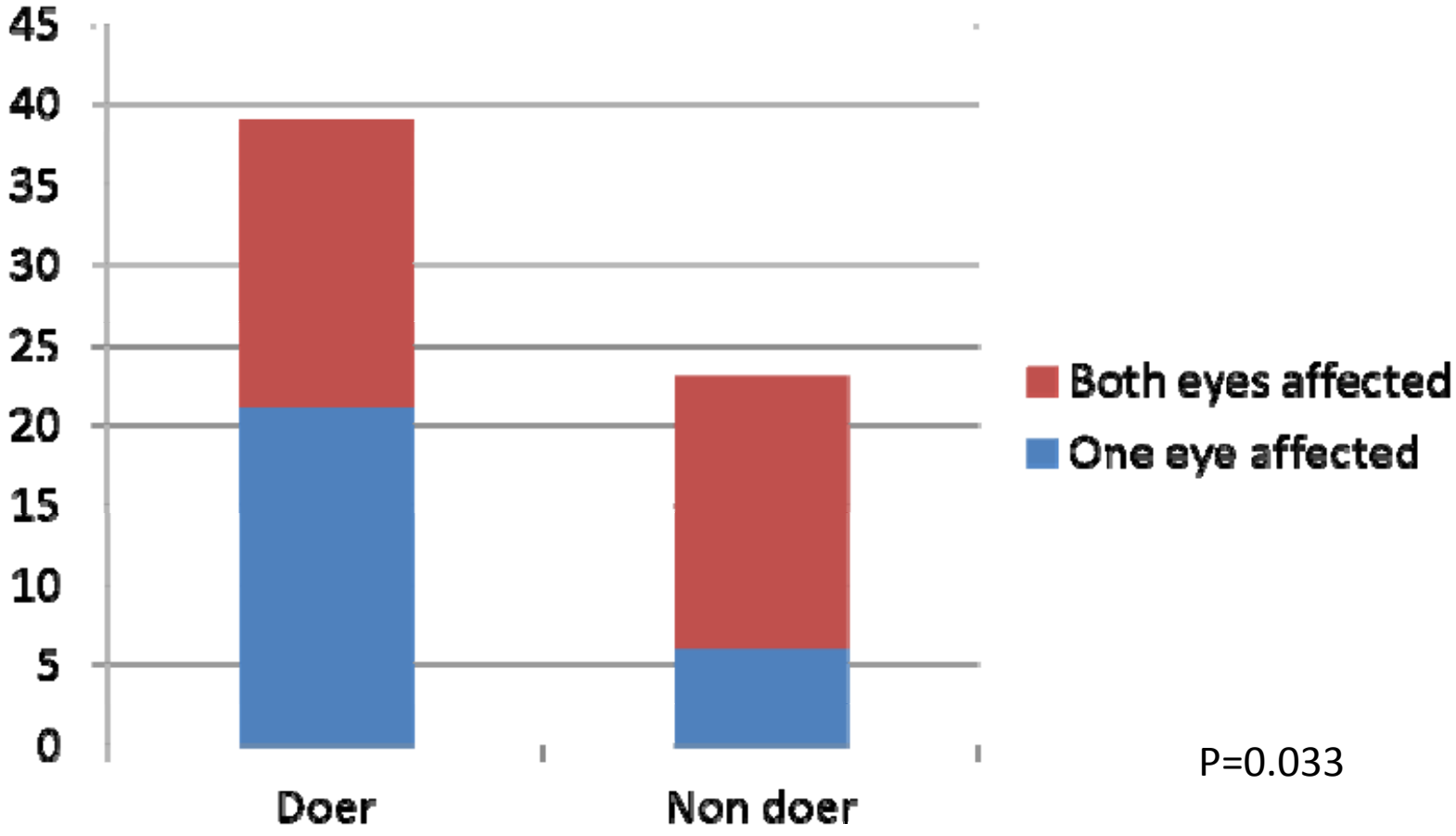
Eye Examinations

Eye Examination

	Doer		Non-doer			
	No	**%**	**No**	**%**	**Total**	**%**
Male	22	56%	14	61%	36	58%
Female	17	44%	9	39%	26	42%
Total	39	100%	23	100%	62	100%
Pearson Ch2 0.11	P=0.731					

- *Is cataract more common in boys than girls, or are girls still being missed in the community?*

Whether One or Both Eyes Affected



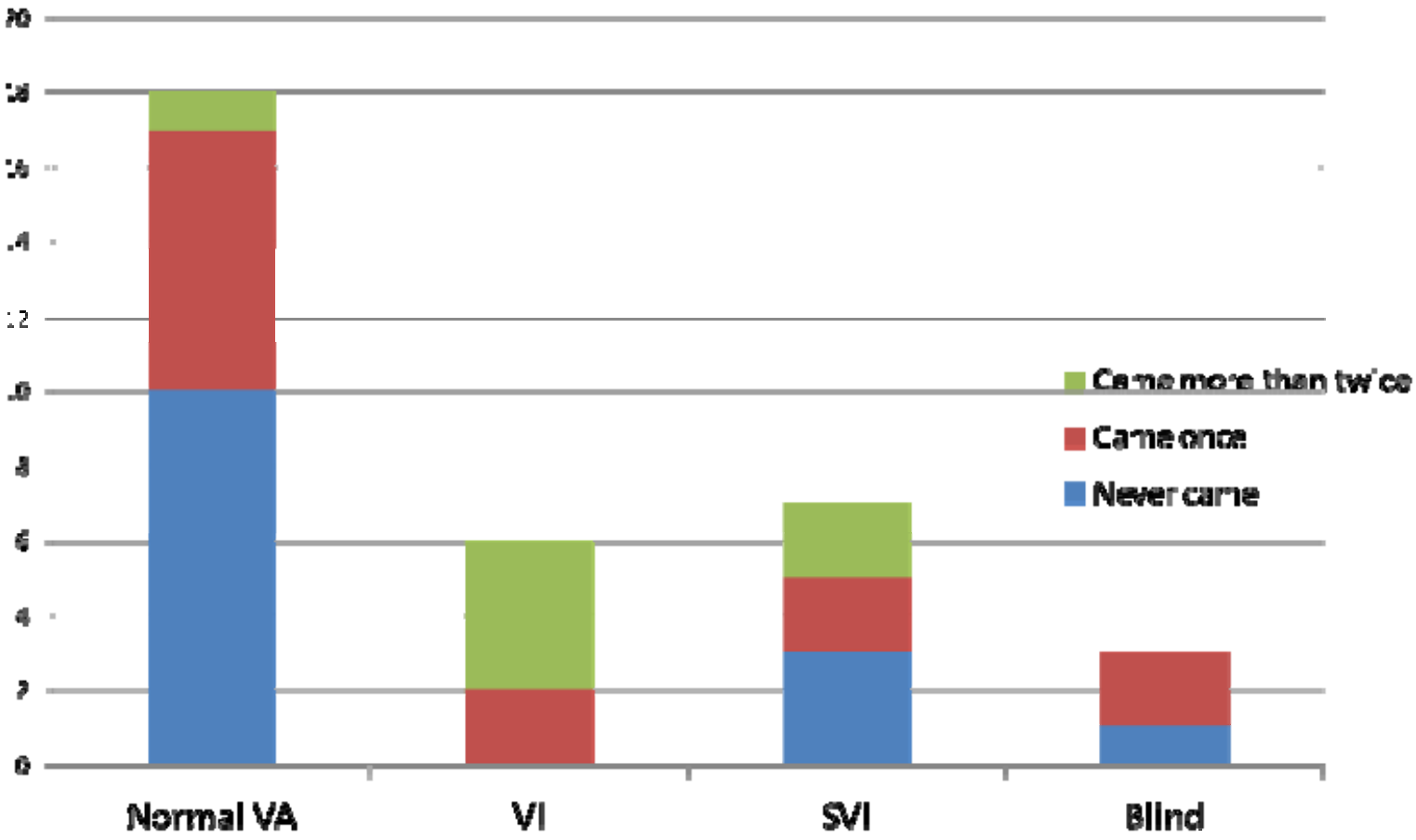
P=0.033

Non doers were more likely to have both eyes affected i.e., worse vision.

Unilateral Cataract or Bilateral Cataract

Unintended Consequence: 48% of Non doers (11/23) have turned into Doers after second intervention.

Follow up rate - 59%



No difference in VA between those who came and those who didn't (p=0.071)

FDG's (N=15)

Mean Age	37 yrs	
Male	44	46%
Female	52	54%
Total	**96**	**100%**
Education Level		
None	21	22%
Primary school	47	49%
Secondary education	28	29%
Total	**96**	**100%**

Findings

- Content analysis complex.
- Findings in agreement with IDI findings between Doer/Non doer.
- Local terminology, symptoms and signs not fully understood.
- Many beliefs/misunderstandings about causes of cataract.

FGD Content Analysis

Example of content analysis	
Fear of untreated cataract	*If the child has a cataract or blindness condition, if she is grown up girl, can meet some men who can't control their libido, they can just rape her and transmit today's HIV virus because she has no sight."* (FGD 5, DOERS, P5). *In our village we put normally pepper leaves in the child eye, we are afraid of going to hospital as some say the eyes will be removed and child's condition will become worse*. (FDG 6,Non Doer,P32).
Future of a blind child	*A blind child has no future. Blindness is good as being dead, there is no future for the blind child. Even the friends who we chart with know that even if you can have something good thing but cannot see, there is no life and future.* (FGD 4, NON-DOERS, P21). *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, DOERS, P2).

Case Studies

- Why do 2 similar families who have been identified in the community behave differently?

Z (Doer) &K (Non doer) Families

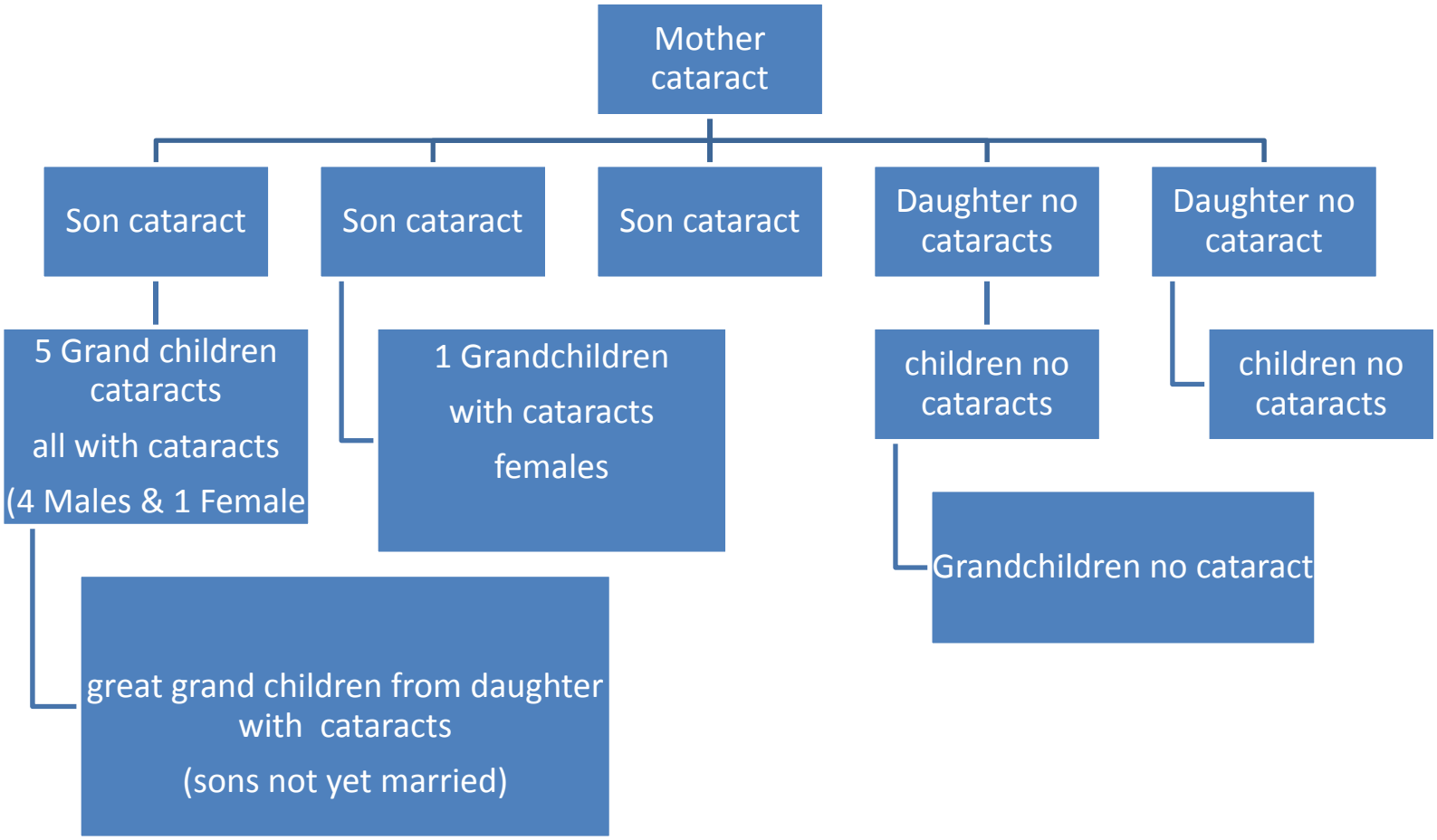
Z family (Doers)

- Both parents not educated; Muslim family.
- Father with cataract, mother OK.
- Five children (4 males, 1 female) with cataract and very high myopia (-0.8Ds -16.0Ds).
- All had surgery; one with poor outcome (HM): rest with VA around 6/60.
- Believes its not God's will
- Believes future of child possible.

K family (Non doers)

- Both parents not educated; Muslim family.
- Four children, 1 boy & 3 girls.
- Mother & daughter 8 yrs are fine.
- Father & 3 children bilateral cataract.
- Initially refused interview.
- Believes nothing can be done about his family, Doesn't want to talk.
- Doesn't want to challenge/change what God has planned for them

Z family (Doers)



Doer / Non Doer Summary

Doer

- Closer to HC.
- Unilateral, less severe.
- Some visual acuity.
- Better off economically.
- Decision making more open – involves community
- Optimistic - positive.

Non Doer

- Further from HC.
- Bilateral, more severe.
- Very poor visual acuity.
- Poor economically.
- Decision making involves influential person.
- No hope – fatalistic.

Interpretation & Lessons Learned

1. Knowledge of cataract among community is limited: we know knowledge does not always result in action.
2. No clear determinants distinguishing Doers from Non doers.
3. Decision making for parents to bring child is complex and should involve several counselling sessions at different levels.
4. Increased acceptance (48%) may be achieved through supportive counselling modules developed on findings.
5. Desired visual outcomes may rarely be achieved in children: but parents are usually very satisfied even with minimal VA.
6. Restoring sight is only one option of addressing childhood blindness: education opportunities must be increased and linked to surgical services.
7. Additional resources are needed

Back to Community for More Research

- Is cataract more common in boys than girls?
- Develop and test effectiveness of comprehensive counselling to increase acceptance.

Acknowledgements

- AED/A2Z for funding this research.
- KCCO for continued support to the programme in Malawi.
- IEF staff for their tireless effort in supporting BICO's initiative for children.
- College of Medicine Social Scientists (anthropologists).
- BICO Research Assistants.

Thank You