

CATARACT SURGERY BARRIERS AND SURGICAL OUTCOMES IN THE
DEVELOPING WORLD

Barriers to Uptake of Free Pediatric Cataract Surgery in Malawi

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ABSTRACT

Purpose: To examine the demographic, sociocultural and socioeconomic factors that prevent families of cataract blind children from accepting free pediatric cataract surgery in Malawi.

Methods: A total 58 parents of 62 children were recruited into the study. Of these, 53 parents partook in in-depth interviews and focus group discussions after the children were screened and the parents offered free cataract surgery. Overall, 37 parents accepted (acceptors) and 16 parents did not accept (non-acceptors) cataract surgery. All interviews were transcribed and iteratively analyzed. Household economic status was quantified using the Progress out of Poverty Index for Malawi.

Results: Acceptors were better off economically ($p=0.13$). Understanding of cataract, its causing blindness and impairment, as well as treatment options, by the decision makers in the families was poor. Decision-making involved a complex array of aspects needing consideration before accepting, of which distance to the health facility was a frequently mentioned barrier. Non-acceptors were more likely to come from twice the distance compared to acceptors ($p=0.0098$). Non-acceptors were more likely to be peasant (subsistence) farmers than acceptors ($p=0.048$). Non-acceptors were more likely to live in a house made of mud bricks with a roof of grass thatch ($p=0.001$). There was no significant difference in acceptance rate between educated and non-educated mothers ($p=0.11$). Intensive counseling as provided in this project increased the likelihood of accepting surgery.

Conclusion: Economic hardship and long distances to health facilities decrease acceptance even of free pediatric cataract surgical services, highlighting that just providing surgery free of cost may not be sufficient for the most economically disadvantaged in rural Africa.

Keywords: Africa, cataract surgery, community child health, pediatric cataract, sociocultural barriers

INTRODUCTION

Around 100 children per million of the overall population are blind due to cataract in Sub-Saharan Africa,^{1–3} but access to cataract surgery is limited. Even within the same geographic region in Africa the annual childhood cataract surgical rate differs widely.⁴

To meet the World Health Organization's Vision 2020 goals and reduce childhood blindness it is essential to reduce barriers to any kind of sight restoring or maintaining surgery.^{5,6} In the past, most studies examined the barriers to cataract surgery in adults only, which does not reflect the situation of cataract blind children.^{7–10}

In Malawi, at least a third of cataract blind children identified at outreach eye clinics did not attend the hospital within 3 months after being identified.¹¹ Reasons for the delay and/or non-attendance included poor communication between the health providers, families and communities; a lack of parental awareness of cataract being treatable; a

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complicated and poorly understood referral process; a lack of financial resources; distance to the hospital; and poor (perceived and actual) outcomes of surgery reinforcing fear associated with surgery.^{11,12} In Tanzania, similar barriers were found to cause a mean delay of 3 years from identification to presentation for surgery.¹³ In the same setting in Tanzania, barriers were identified at both the family/community level and the socio-organizational level.¹⁴

In the past, interventions addressing some of these barriers¹⁵ have increased the number of children identified in the community, but have often failed to increase the number of children attending for cataract surgery or follow-up examinations despite parents being provided with information and transport refunds.¹⁶ This highlights the complexity of barriers related to non-attendance suggesting that providing information and transport refunds alone are not sufficient. Against this background we conducted this study to better understand barriers to the uptake of pediatric cataract surgery in Malawi in order to redesign community interventions to increase uptake of services for blind and visually impaired children.

MATERIAL AND METHODS

Study Population and Sample

The project was undertaken from January 2011 to August 2011 in Zomba, Mangochi and Balaka districts in southern Malawi with a population of 1.5 million (630,000 children). A population-based childhood blindness study was conducted in these districts between 2008 and 2010 that resulted in a list of all blind and visually impaired children.¹⁶

The research team used this community research database of children, and another hospital database of 200 children that received cataract surgery at the Lions Sight First Eye Hospital (LSFEH) during the same period. These databases were used to identify children who underwent cataract surgery (listed in both databases) and children who were blind from cataract but did not attend the LSFEH for cataract surgery (listed in the community database but not the hospital database). Ethical approval was obtained from the University of Malawi College of Medicine Research Committee, and every participant and their respective parent gave written informed consent before being included into the study. The study adhered to the tenets of the declaration of Helsinki.

Study Design and Conceptual Framework

This operational research employed a mixed methods study methodology. Qualitative data collection methods, focus group discussions (FGDs) and in-depth

interviews (IDIs) – separate for both acceptors and non-acceptors – were used to collect data from the children's parents). The critical behavior examined was whether a family with a child blind from cataract acted on the advice of the health worker and came forward for 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 examined were centered around skills, access, cultural beliefs and consequences of action/non-action. The internal behavior determinants examined were centered around self-efficacy, perceived social norms, knowledge, attitudes and perceived risk.

Data Collection Methods

Parents who did not accept cataract surgery for their child/children were classified as non-acceptors, parents who did accept cataract surgery for their child/children were classified as acceptors. Both IDIs and FGDs were unstructured, used open questions, and were guided by emerging themes in a flexible and continuous manner with little interference from the interviewer or FGD moderator. Qualitative data was gathered using 53 IDIs with parents, 21 IDIs with children, and 15 FGDs until thematic saturation was reached. The IDIs and FGDs were complemented by a total of four family case studies. Interviews and FGDs were conducted within the community. FGDs were conducted separately for acceptors and non-acceptors. All interviews were transcribed and iteratively analyzed.

Assessment of Socioeconomic Status

To quantify poverty we used the Progress out of Poverty Index (PPI) for Malawi.^{17*} The Malawi PPI is derived from the Grameen Foundation (Washington, DC, USA). The PPI is a tool for micro-finance programs and consists of 10 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.¹⁷

A total of 52 IDIs of families were completed to identify the socioeconomic characteristics that may affect their access to eye care services.

*The development and update of every Progress out of Poverty Index (PPI) is coordinated by the Grameen Foundation and includes the input of a variety of stakeholders. The Grameen Foundation usually tests a PPI in the field and creates supporting documentation in the interest of transparency. Mark Schreiner of Microfinance Risk Management, LLC is the developer of the PPI.

Data Analysis

Qualitative data was analyzed thematically, based on grounded theory.¹⁸ The themes were coded by two independent social scientists from the College of Medicine, University of Malawi. In case of any discrepancies found between the interpretations, the material was reviewed in a meeting and the issue was resolved through agreement. A final report was produced using direct quotations from participants.

We used a qualitative approach and present citations of the FGDs and IDIs. Quantitative data were entered in EpiData (EpiData Association, Odense, Denmark), and imported and analyzed using Stata 10 (StataCorp LP, College Station, Texas, USA)

RESULTS

Overall, 62 children were identified. As several families had more than one affected child, a total of 58 parents were recruited for the sociodemographic and socioeconomic interview. Of these, 53 parents partook in IDIs and 15 in FGDs (Table 1). All parents who participated in FGDs participated in IDIs as well. Of these 53 parents, 37 accepted free surgery (acceptors) for their child or children, and 16 did not (non-acceptors). An additional 15 FGDs and 4 family case studies were conducted separately for both acceptors and non-acceptors (Table 1).

Children of acceptors and non-acceptors were not different in age (mean age 9.5 years) or sex (42% girls). There were more boys than girls examined, but the difference was not statistically significant ($p=0.731$). A total of 74% of children of non-acceptors were bilaterally blind (17/23) compared to 46% (18/39) of children of acceptors ($p=0.033$). There was no significant difference in acceptance rate between educated and non-educated mothers ($p=0.11$).

Understanding of Cataract

During the FGDs, participants were shown a photograph of a child with cataract. In both groups the majority identified the photographs as “ng’ala” in Chichewa, the local language. Some FGD participants, especially among the non-acceptors confused the

photo as “ana m’maso,” literally a painful wound in the eye or cornea scarring (FGD 10, non-acceptor, all).

Discussing assumed causes of cataract, participants stated that caratact could be caused by foreign bodies, infection and unhygienic practices. A hereditary component of pediatric cataract was not mentioned.

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-acceptor, P24)

Another frequently stated belief was that sexual intercourse prior to birth of the child could cause cataract.

The majority of participants associated cataract with vision impairment, but only a minority thought of cataract as a cause of blindness. Blindness was commonly referred to as the inability to perceive light, whereas any light perception was not referred to blindness.

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. (FGD 3, acceptor, P20)

Treatment for Cataract

Some participants reported that ng’ala could be treated by attending hospital. However, most respondents did not know how cataracts were treated. All participants who reported cataract to be curable had witnessed children regaining vision after cataract surgery.

However, it was also mentioned that there were rumors in the area that linked cataract surgery to blindness and participants urged each other to dispel such rumors in their communities.

Health-Seeking Decisions in a Family

Participants stated that either the husband or the wife decides, through dialogue with the other, on whether to take the child to hospital. Their motivation is to avoid the burden of caring for a blind child. However, a number of participants observed that it is usually the mother who initiates hospital attendance because she is the primary caregiver, while the husband is often away working. A minority of respondents mentioned that it is the duty of the husband to decide to take the child to hospital. The majority of participants mentioned that usually men do not promote healthcare-seeking behavior, either ignoring

TABLE 1. The number of in-depth interview (IDI) and focus group discussion (FGD) participants by acceptor and non-acceptor status for pediatric cataract surgery in Malawi.

	Acceptor	Non-acceptor	Total
IDI – parents	37	16	53
FGD – community	9	6	15
Case study families	2	2	4

the child or taking the child to a herbalist first instead of the hospital.

Most participants observed that blind children have no future as they have no chance to be educated. This was the main reason stated by several participants for acceptance of cataract surgery or healthcare seeking.

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-acceptor, P21)

Overall, similar topics emerged in IDIs and FGDs with acceptors and non-acceptors, with no significant differences between the two groups.

Family Case Studies

Acceptor and non-acceptor families were not different in their understanding of cataract, its treatment, reasons for and barriers to healthcare seeking or assessment of the impact of blindness on a child's life. The in-depth family case studies highlight this and two examples are presented in Table 2.

Socioeconomic Status of Participants

Non-acceptors were more likely to live twice the distance away from a health center compared to acceptors ($p=0.0098$; Table 3). Non-acceptors scored lower on the PPI, with 64% of families living below the national poverty line and 86% living on less than US\$1.25 per day (2005 purchasing power parity, PPP; Table 3). In comparison, only 39% of acceptors lived

below the national poverty line and 69% on <US\$1.25 per day (2005 PPP; Table 3). Non-acceptors were more likely to be peasant (subsistence) farmers than acceptors ($p=0.048$; Table 4). Non-acceptors were more likely to live in houses made of mud bricks and a roof of grass thatch ($p=0.001$; Table 4). Although both acceptors and non-acceptors were poor by any standard, the non-acceptors were poorer. Assessing maternal education, mothers who accepted cataract surgery were more often educated (59%) compared to non-acceptors (52%), though this difference was not significant ($p=0.11$; Table 4).

DISCUSSION

The main finding of our study is that families who were better off economically and lived closer to a health facility were more likely to accept free pediatric cataract surgery in Malawi. There was no significant difference in acceptance rate between educated and non-educated mothers ($p=0.11$), though the qualitative data showed that children's health is a major concern of their mothers. This indicates that distance and other hidden costs associated even with free

TABLE 3. Sample of characteristics between acceptors and non-acceptors of pediatric cataract surgery, Malawi.

	Acceptors	Non-acceptors	<i>p</i> Value
Malawi Poverty Level Index	32	24	0.13
Distances (mean km)			
From village to health center	2.4	5.5	0.0098
From health center to district hospital	25.8	27	0.92
From district hospital to tertiary hospital	120.8	106.8	0.5

TABLE 2. Two family case studies for acceptance of pediatric cataract surgery in Malawi.

"K" family, Zomba District	"Z" family, Zomba District
<ul style="list-style-type: none"> • Four children, 1 son and 3 daughters; aged 14 years (girl), 11 years (girl), 8 years (girl), and 2 years (boy). • Father and 3 children had bilateral cataract. • Strict Muslim family, poor, not educated and don't send their children regularly to school. • Initially refused interview but agreed after a neighbor intervened. Parents avoided the meeting the next morning and left for their garden work despite knowing of our planned visit. • On interview, the parents believed that nothing could be done about their family's vision problems and did not want to talk further. The parents state that they will never go to hospital under any condition. 	<ul style="list-style-type: none"> • Five children, 3 sons and 2 daughters (the children are now adults and the daughters have their own families). • Mother had cataract while the father did not. • The 3 sons had bilateral cataract while the 2 daughters did not. • Grandchildren (from the sons) had cataract while the daughter's children do not. • Strict Muslim family, poor, not educated but they send their children regularly to school. • All children of school age go to school. • Parents of children who have had cataract were eager to take their child to the hospital early in their lives (at 6 months). • Parents also came for the post-surgery follow-up examinations. • 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.

TABLE 4. Information about parents of children with cataract, by acceptance or non-acceptance of pediatric cataract surgery, Malawi.

Source of income	Acceptors, <i>n</i>	%	Non-acceptors, <i>n</i>	%	Total, <i>n</i>
Peasant farmer ^a	18	46	15	79	32
Small scale business	10	26	4	21	14
Employed manual labor	4	10	0	0	4
Employed skilled (e.g. carpentry, tinsmith)	7	18	0	0	7
Total	39	100	19	100	58
House construction					
Mud bricks with grass thatched roof ^b	9	23	15	79	24
Burnt bricks with grass thatched roof	15	38	4	21	19
Burnt bricks with metal sheet roof	15	38	0	0	15
Total	39	100	19	100	58
Mothers' education level					
Not educated	16	41	12	48	28
Educated ^c	23	59	7	52	30
Total	39	100	19	100	58

^aNon-acceptors were more likely to be peasant (subsistence) farmers than acceptors ($p=0.048$).

^bNon-acceptors were more likely to live in houses made with mud bricks and a roof of grass thatch ($p=0.001$).

^cThere was no difference in acceptance rate between educated and non-educated mothers ($p=0.11$).

pediatric cataract surgery limit acceptance considerably.

Perceived barriers were distance, no felt need, a preference for traditional healers/herbalists, fear of the operation, and fatalism/acceptance of cataract as a hereditary and thus God-given fact. Many participants reported that mothers usually were more likely to seek healthcare for their children than fathers, as mothers are the primary caregivers and fathers may be away from the family for a considerable amount of time working. Some of this is reflected in studies conducted in Tanzania, where primary barriers were found to exist at the community level rather than the provider level.¹³ Bronsard and co-authors emphasized therefore the importance of in-depth investigations into barriers to healthcare seeking and use of services as part of ongoing service provision and improvement.¹⁴

Awareness towards health services, understanding disease, making a decision within the family and the community is a complex process influenced by many factors, especially the level of education and standard of knowledge of the parents.¹⁹ In Togo, Balo and colleagues found that lack of awareness regarding eye diseases was the main constraint in the national Vision 2020 initiative.²⁰

Based on these findings, mothers seem to be a key driver in the decision-making process, unless the father actively disagrees and prefers their children not to undergo cataract surgery. Based on this and our finding that children's health is a major concern of their mothers, specifically educating mothers at outreach eye clinics promises to increase acceptance rates. Other educational interventions, focusing on general skills and literacy, may provide further synergies. However, this is outside of what most eye health providers can realistically achieve.

Based on our findings, addressing hidden costs by providing transport, and lowering other hidden costs where necessary may increase uptake of pediatric cataract surgery services. Following the IDIs and FGDs, 11 families who previously did not accept surgery came to the hospital to have their affected child treated. Thus, intensive counseling at all levels, but in particular during outreach eye camps, may further increase uptake of pediatric cataract surgery.

Strengths of this study are the FGDs and IDIs which are ideal tools to investigate parents' beliefs towards their blind children's cataracts and treatment options, as well as associated barriers to healthcare-seeking and acceptance of surgery. 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. By using different methods such as IDIs, FGDs and case studies, data were triangulated and their validity increased. Limitations of this study are the relatively small sample size, the lack of confirmatory quantitative data, and the relatively short follow-up between advising cataract surgery at outreach and follow-up investigating acceptance/non-acceptance. Distance to the health facility may reflect economic status of the interviewed families, whereby families who are better off can afford to live closer to an urban center with a health facility.

In summary, parents of cataract blind children who did not accept free cataract surgery were poorer and lived significantly further away from the nearest health center. Non-acceptors were less educated, had a lower income, and lived in less permanent homes compared to acceptors. In addition, intensive

counseling at any stage seems necessary to encourage acceptance. Acceptance may further be increased by educating mothers, not only about the particular health program but also in general. Future programs should address these barriers by providing services not only free of any direct cost, but also free of or low in indirect and hidden costs as well as include comprehensive counseling of parents.

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DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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