



Cataract Surgery Uptake in Kenya

2019

Authors:

Eunice W Mailu¹; Stevens Bechange²; Moses Chege¹; Maurice Abony¹; Emma Jolley³ & Elena Schmidt³

From ¹Sightsavers Kenya; ²Sightsavers Uganda; and ³Sightsavers United Kingdom.

Acknowledgments

This research benefitted from the thoughtful contributions of many individuals and organisations. We would particularly like to express our deep gratitude to:

- The many individuals who invested time and thought to take part in the study.
- Amref Health Africa ESRC, NACOSTI and health facility managers in Samburu, Turkana and Laikipia for their guidance and support.
- Sightsavers country office in Kenya for their organisational and logistical support.

- Sightsavers global teams, specifically Ms Ziporah Mugwang'a, Effie Rarite, Mr Moses Chege and Dr Tesfaye Adera for their overall technical assistance and support.
- Dr Mary Nyikuri for assistance with data analysis.
- Special thanks to Elizabeth Oyugi for overall leadership on all aspects of the study.

This study was funded by the UK Department for International Development (DFID) through a grant to Sightsavers. However, the views expressed in this report are strictly those of the authors and do not necessarily reflect the UK government's official policies

Table of Contents

Acknowledgments	2
Table of Contents	3
List of Tables	3
Acronyms and Abbreviations	4
Summary	1
Introduction	2
Methodology	5
Study design and sampling.....	5
Data collection	6
Data management and analysis	6
Ethical considerations.....	6
Results	6
Quantitative findings	6
Qualitative Findings	9
Factors influencing cataract surgery uptake	10
Discussion	17
References	22

List of Tables

Table 1: Characteristics of patients who were screened, found with operable cataract and referred for surgery	7
Table 2: Uptake of Cataract Surgery (based on available records)	7
Table 3: Characteristics of patients referred and operated for cataract (based on 168 records that could be linked between screening and surgery registers)	8
Table 4: Number of interview and FGD participants per region	9

Acronyms and Abbreviations

AMREF	African Medical and Research Foundation
CATCH	Coordinated Approach to Community Healthy Eyes
FGDs	Focus group discussions
CHVs	Community health volunteers
GBD	Global burden of disease
HCWs	Health care workers
IAPB	International Agency for the Prevention of Blindness
IDI	In depth interviews
LMICs	Low- and middle-income countries
OCOs	Ophthalmic clinical officers
ONs	Ophthalmic nurses
NACOSTI	National Commission for Science, Technology & Innovation
TT	Trichiasis trachomatis
WHO	World Health Organization



Summary

Background: Cataract remains the leading cause of blindness in low- and middle-income countries. This study sought to understand cataract surgery uptake in Kenya and investigate individual and programme level factors that influence the uptake. The study was nested in the Coordinated Approach to Community Healthy Eyes (CATCH) programme, a four-year cataract programme integrated within trachoma outreach camps.

Methods: This was a mixed method study that combined quantitative and qualitative data collection approaches. Quantitative *patient data* was abstracted from screening and surgery registers in two counties, Turkana and Samburu. Qualitative data was collected in three counties: Turkana, Samburu and Laikipia. All data were collected between July 2016 and June 2017. Data were analysed using STATA 14 and NVIVO software. Ethics approval was granted by the African Medical and Research Foundation Health Africa Ethics and Scientific Review Committee.

Results: During the evaluation period, 621 patients were identified and referred for cataract surgery in two of the three

studied counties. The records of surgery were available for 168 (27.1 per cent) of these patients. In the same period, the total number of patients operated in the study counties was 223, with 75.3 per cent (168) of them being referred by CATCH. The most likely explanation of this discrepancy is the gaps in documentation at the hospital level, with patients operated recorded under different names and addresses than those at the screening camps. However, even if we assume that all 223 patients operated in the study period were from CATCH camps, the uptake of surgery appears to be low, at around 35 per cent. This uptake is different from the internal programme records, which reported the uptake rate of around 75- 80 per cent. As data collection in this study was retrospective, the finding suggests that a large proportion of records of cataract patients was either never kept or had been lost by the time of the study. Qualitative data shows that, several individual and programme factors have influenced the uptake of cataract surgery. Individual level factors included; cultural beliefs and rumors, fears, availability of family support, distance to health facility and concerns about loss of productive time and home security. Programme factors included waiting time and cancellations; numbers, skills and

attitudes of staff; quality of counselling and follow up and communication between different teams.

The study also provided some interesting insights into the relationship between programmatic and individual level factors. It shows that a well organised and appropriately managed service with positive attitudes of staff and good staff communication, creates positive views of a surgery in the community and increases surgery uptake. On the other hand, busy, overcrowded and poorly managed camps and facilities, staffed with tired, overworked and unfriendly personnel, coupled with delays and cancellation of treatments, create negative attitudes and discourage patients from going to surgery.

Conclusion: The study concludes that among multiple factors determining patient health seeking behaviour, there are cultural and social factors that a three to four-year programme supported by an international donor, may find difficult to address. However, there are service level factors which are in control of such programmes, including numbers and training of staff, quality of community mobilisation campaigns and communication between different teams. These factors are equally critical and can either increase or significantly decrease

demand for and uptake of cataract surgery.

The study has a number of programme implications regarding adequate numbers and training of staff; quality of community mobilisation campaigns; patient counselling and information; prevention of programmatic bottlenecks; engagement of community champions; access for patients at high risk of drop out; surgery follow up and patient data and information systems.

Introduction

The most recent estimates by the World Health Organization (WHO) suggest that 2.2 billion people live with some form of vision impairment worldwide; and the Global Burden of Disease (GBD) study estimates that 188.5 million people have mild vision impairment, 217 million have moderate to severe vision impairment and 36 million are blind (1, 2).

The majority of the world's visually impaired people live in low and middle income countries (LMICs) (3); and about 65 percent of all people with visual impairments are aged 50 years and older (2).

Cataract is the leading cause of blindness in LMICs (2). In Africa, cataract



contributes to approximately half of all cases of blindness. Although access to cataract surgery is one of the key priorities identified in the WHO Global Action Plan, which aims to reduce the burden of avoidable visual impairment, in many developing countries, multiple barriers preclude patients' access to surgery (3, 4).

Patient health seeking behaviour determines uptake of surgery, while health seeking behaviour itself is influenced by multiple factors, including patient's knowledge of a health issue, their perception of risk, social and cultural norms and characteristics of health services (5). Therefore, the success of any health intervention depends on both its accessibility and acceptability, both of which relate to broader individual and social factors (6). The availability of literature on health seeking behaviour in LMICs varies by context and type of health intervention. A prominent view in the studies that are available is that health seeking behaviour in these settings is influenced by geographical, social, economic, cultural and organisational factors, all of which can act either as barriers or facilitators of service uptake (7). The 'three delays' model which has been widely used in maternal health studies suggests that delays in

accessing health care may happen at three levels: delays in making a decision, delays in visiting a health facility, and delays in receiving adequate treatment (8). A recent systematic review of studies of eye health seeking behaviour in Africa showed that a range of factors, including socio economic characteristics, geographic location, social and cultural norms and organisation of health services, influence the uptake of cataract surgery (3).

Several earlier studies suggested that user fees and transport costs are a significant barrier to uptake of cataract surgery. However, evidence also suggests that even in the contexts where the impact of these barriers is minimised through providing free surgery and transportation, problems with the uptake of surgery exist. For example, a study conducted in rural Kenya found that nearly half of the patients offered a free surgery refused it (9). The reasons given by the patients were the negative experiences of others, the lack of social support, and the perception that free services were of poor quality.

The study presented here was designed to better understand patient health seeking behaviour and complement the evidence base on the uptake of surgery in the contexts, where the surgery is

available free at the point of use. It is envisaged that the findings will be particularly useful in the development of patient mobilisation campaigns and organisation of cataract services and help to maximise the surgery uptake and efficiency of services.

The CATCH Program

The Coordinated Approach to Community Healthy Eyes (CATCH) programme was a four-year intervention funded by the UK Department for International Development UKAid Match funding stream. It was implemented by Sightsavers and their partners in five countries (Kenya, Uganda, Zambia, Mozambique and Malawi), with the aim to improve access to eye health services and reduce avoidable blindness among people living in trachoma endemic areas. The programme applied an integrated approach to screening and treatment of patients with trichiasis trachomatis (TT), cataract and other eye conditions. Patients were recruited through TT outreach camps, where they underwent eye health screening and a general eye examination. If diagnosed with an operable cataract, they were referred to the nearest district hospital for surgery at no cost to the patient. Transport from the community to the health facility was also provided in most cases.

In Kenya, the programme was implemented in Turkana, Samburu, Laikipia and Kajiado. The camp mobilisation in Kenya was mainly through Community Health Volunteers (CHVs) who could easily move around the villages. The communities targeted by the project in the 4 counties (Turkana, Kajiado, Samburu and Laikipia) live in either community (manyattas) or semi urban settings which made it easy for the CHVs to mobilise them.

In most settings, communities would be informed that an eye camp was to be held at a certain location and everyone with eye problems was encouraged to come and have their eyes checked. Screening at the camps was conducted by Ophthalmic Clinical Officers (OCOs). Those diagnosed with bacterial conjunctivitis were treated on site. Patients identified for surgery were given information about their condition and transported to the health facility. At the surgical health facility there was also a CHV responsible for patient support. Patients were then taken through the surgical procedure and what was expected of them; and were given a consent form to sign. The surgery was done on the day of admission and the post-operative follow up was completed on the following day. Patients were also



given information on how to take care of their eyes, the date of the next follow up appointment and were then discharged.

Aim of the study

The aim of this study was to understand cataract surgery uptake in the context of a community-based eye care intervention that eliminated some of the known barriers to cataract surgery uptake.

Objectives

The specific objectives of the study were as follows:

1. To characterise the level of cataract surgery uptake in a community-based eye health programme across multiple settings.
2. To explore the individual, community and programme level factors that influence the uptake of cataract surgery
3. To evaluate the decision-making processes among individuals referred for cataract surgery including the role of gender and disability

Methodology

Study design and sampling

This was a mixed method study that adopted both qualitative and quantitative data collection approaches. To collect quantitative data, a retrospective chart abstraction was conducted for patients screened and referred for cataract surgery by the CATCH programme between July 1st, 2016 and June 30th, 2017. Based on the programme data, we anticipated a minimum of 514 patient records completed in this evaluation period. In depth interviews (IDIs) and focus group discussions (FGDs) were used to collect qualitative data with purposively selected individuals (patients, health care workers and community leaders).

The study was conducted in three out of the four CATCH programme counties in Kenya, namely: Turkana, Samburu and Laikipia. The rationale for selecting the three counties was that they had conducted significantly more surgical camps than Kajiado and the necessary number of patient records could be obtained with greater ease. However, quantitative data was collected only from Turkana and Samburu.

Data collection

Patient data was abstracted from the screening and surgery registers using mobile devices running Kobo software.

To collect qualitative data, trained data collectors conducted in depth interviews and focus group discussions using semi structured topic guides. Patients were selected purposefully to represent both men and women and those who were referred to and operated on; and those referred to but not operated on.

Community leaders and health care workers were also purposefully selected and interviewed.

Data management and analysis

STATA version 14 ® (College Station, Texas 77845, USA) was used for quantitative data management and analysis.

Qualitative interviews and FGDs were audio recorded, transcribed and translated for analysis. Notes were also taken to capture nonverbal communication and any other information of interest. The transcripts were managed and analysed using NVivo 12 software.

Ethical considerations

Ethical approval was obtained from the African Medical and Research Foundation (AMREF) Health Africa Ethics and Scientific Review Committee. Permission to carry out the study was obtained from the National Commission for Science, Technology & Innovation (NACOSTI). Written informed consent was obtained from all study participants.

Results

Quantitative findings

The records obtained from the programme show that in total, 621 patients were diagnosed with cataract and referred for cataract surgery through the CATCH programme in the two study sites during the evaluation period. Over 56.8 per cent of all referred patients were from Turkana County.

Data on sex and age were available for 615 patients only while for region data was available for 621 patients. The majority of patients referred for cataract surgery were aged 60+ years (91 per cent in Samburu and 77.5 per cent in Turkana). In both Samburu and Turkana there were more females (51.9 per cent and 53 per cent respectively) referred for

surgery than males (48.1 per cent and 47 per cent respectively).

Table 1: Characteristics of patients who were screened, found with operable cataract and referred for surgery

Stratification of the Screened population by sex and age				
	Female		Male	
Age group	N =325	%	N =290	%
30-60	56	(17.2)	44	(15.2)
60+	268	(82.5)	245	(84.5)
<30	1	(0.3)	1	(0.3)
Stratification of the Screened population by region and sex				
	Samburu		Turkana	
Gender	N =268	%	N = 353	%
Female	139	(51.9)	187	(53.0)
Male	129	(48.1)	166	(47.0)
Stratification of the screened population by region and age				
	Samburu		Turkana	
Age group	N =268	%	N = 347	%
30-60	24	(9.0)	76	(21.9)
60+	244	(91.0)	269	(77.5)
<30	0	(0.0)	2	(0.6)

Records of surgery were available for 168 (27.1 per cent) patients referred through screening at the CATCH camps.

However, the hospital surgery registers show that in the evaluation period a total of 223 patients were operated on for cataract, with 168 (75.3 per cent) of them being referred by CATCH. This suggests that either 55 of the operated patients

were walk ins or there was a mismatch of screening and surgery records. However, even if we assume that all 223 patients operated by the hospital were referred through CATCH, the uptake of surgery is low, 223 out of 621 patients or 35.9 per cent.

Table 2: Uptake of Cataract Surgery (based on available records)

Uptake of Surgery among screened		
Surgery uptake	No. screened	Per cent
No	453	(72.9)
Yes	168	(27.1)
Total	621	

Uptake of surgery by screening status		
Screened	Surgery uptake	Per cent
No (Suspected walk ins or mismatched records)	55	(24.7)
Yes	168	(75.3)
Total	223	

Based on the linked records, there were more males (78.9 per cent) than females (71 per cent) among those operated for

cataract. Over 75 per cent of operated patients were aged 60+ years and over 89 per cent were from Turkana ([Table 3](#)).

Table 3: Characteristics of patients referred and operated for cataract (based on 168 records that could be linked between screening and surgery registers)

Referred and operated for cataract		
Variable	No.	(Per cent)
Gender		
Male	97	(78.9)
Female	71	(71.0)
Total	168	
Region		
Samburu	71	(62.3)
Turkana	97	(89.0)
Total	168	
Age Group		
<30	0	(0.0)
30 60	19	(73.1)
60+	146	(75.6)
Total	165	

Qualitative Findings

To collect qualitative data; 6, 8, and 10 FGDs were conducted in Laikipia,

Turkana and Samburu respectively, while the number of individual in depth interviews was 39, 35, and 33 respectively.

Table 4: Number of interview and FGD participants per region

	Turkana	Samburu	Laikipia	Total
Category of Interview	IDIs			
Female Patients Operated	10	5	7	22
Female patients not Operated	5	6	8	19
Male Patients Operated	1	3	10	14
Male patients not Operated	4	7	4	15
Community Leaders & CHVs	8	9	6	23
Health Care Workers (OCOs/ONs)	7	3	4	14
Total In depth interviews	35	33	39	107
	FGDs			
Female Patients Operated	2	1	1	4
Female patients not Operated	0	2	1	3
Male Patients Operated	1	1	1	3
Male patients not Operated	0	1	0	1
Male Patients operated and not Operated	1	0	1	2
Males and Females patients operated	0	2	0	2
Males and Females patients not operated	1	1	0	2
Female patients operated and not operated	2	0	0	2
Community Leaders & CHVs	1	2	2	5
Total Focus Group Discussions	8	10	6	24
Total Interviews (Both FGDs and IDI)	43	43	45	131

Factors influencing cataract surgery uptake

For the purpose of this study, factors affecting patients' decisions about the surgery have been broadly organised into surgery motivators and surgery barriers, and the findings within each group were divided into two themes (1) individual and community level factors and (2) programme / health system factors.

Surgery motivators

Individual and community level

There were five main reasons given by the patients, who undertook cataract surgery explaining why they agreed to the surgery, i) family responsibilities; ii) improvements in livelihoods; iii) family support; and iv) positive experiences of others.

Family Responsibilities

A number of patients reported that they had accepted the surgery because they had family responsibilities and their restored sight would help them to better take care of their family. Some patients had young children in their household, who needed money to pay their school fees. Others wanted to be able to work again and provide for their families.

Improved livelihood

Some patients said that they took up surgery because they wanted “*to fully restore their vision*” and improve their livelihood that had deteriorated due to visual impairment. Some said that the reason they went for the surgery is because they wanted to become independent and stop being a burden to others; “*The reason I looked for a doctor was because I wanted to do things for myself*”. Others feared that if they lost their sight, they would not be able to carry out their income generating activities. Others wanted to have their sight restored so that they could perform their routine household chores.

Family support

Having family support in terms of accompanying the patient to the hospital, as well as taking care of them post-surgery, motivated patients and facilitated the uptake of surgery. For example, participants that took part in an FGD acknowledged that if they had not had a guardian, such as their spouse, children or grandchildren, they would have felt helpless in the hospital.

Positive experiences of others

A number of participants said that positive testimonies of others in their community, their ability to move and be independent

helped in making a positive decision about the surgery. Patients who saw someone who had undergone the surgery and was able to see well, felt encouraged to go for surgery. CHVs also reported that previously operated patients who were able to see and carry out their daily activities, were used as champions for improving the uptake of surgery.

Some patients also reported that some of their friends and neighbours who had declined the surgery, decided to go for it after seeing them happy and able to see again.

Programme or health system level

In relation to the programme or health system, there were two main reasons given by the patients who undertook cataract surgery explaining why they agreed to the surgery, i) provision of free services and ii) positive attitudes of healthcare staff.

Provision of free services

One of the key factors that motivated patients to agree to undergo surgery was the provision of free services (transport and surgery). Some patients even said that if it were not for the free transport they would not have gone for the surgery and others said that if they were told to pay for the surgery, they would not have managed because it could be very

expensive for them to afford. Many patients were also happy about free food provided at the facility.

Positive attitudes of healthcare staff

Patients expressed their happiness due to the good care offered to them at the health facilities. The CHVs reported that people in the community always asked them when the eye health team would come because of the good quality of care offered. Some patients said that the way health care workers were listening to them, and the way they answered their questions, was respectful and attentive; these patients felt satisfied with the services. Those little gestures motivated the patients and made them talk positively about the programme.

Surgery Barriers

Individual and community level

Individual and community level factors preventing patients from taking up surgeries were organised under several themes as follows: i) rumours and cultural beliefs about eye problems; ii) fear; iii) lack of social support; iv) distance and transport costs; v) loss of productive time; vi) insecurity; and vii) gender related factors.

Rumours and cultural beliefs about eye problems

Beliefs and rumours were mentioned by health care workers, community leaders and even patients. The desire to try traditional medicines was reported to delay health seeking behaviour of some community members. Old people were said to feel that restoration of eyesight after surgery was unnecessary as they were about to die.

The fear of having their eye replaced by an eye that belonged to either a goat or a chicken was another reported rumour discouraging people to take up surgery.

Other common beliefs mentioned were that cataract problems were inherited and therefore were untreatable. People from the Turkana community feared that they would be told to remove their beads.

The use of language and especially medical terms, such as surgery, which in the local Turkana dialect means “scrapping” also generated rumours and was mentioned by both HCWs and CHVs.

One patient explained how she understood the eye problem she had: *‘I have had an eye problem that came as a result of witchcraft. Someone poured water in the fire when my husband died. I developed an eye problem. I became blind and I couldn’t see anything’.*

Fear

In all counties, fear was mentioned to affect cataract surgery uptake, as many patients believed that their eyes could be damaged by the surgery and they would become blind. Fear was the main reason named by those patients who refused cataract surgery in this study. Patients feared losing their eyesight and their livelihoods.

A large number of patients interviewed were illiterate, which also led to fears and incorrect information about the surgery. Fears were reported by both male and female patients.

Lack of social support

Lack of social support in terms of either a family member or a neighbour accompanying the patient to the hospital was also reported as a barrier to taking up the surgery. A number of patients also reported that they had declined the surgery because they didn’t have anyone to take care of their home and domestic animals while being away. For example, a female patient from Samburu had declined the surgery twice because she did not have anyone to look after her house.

Some patients believed that the surgery could lead to more significant disability and immobility, which was a challenge for

them, as they lived on their own and did not have any family to help them.

Cost and distance

The role of financial resources in seeking eye care services was considered important by all participants. Some patients reported that they needed money to pay for transport and for post-surgery medication. Patients talked about distances to the facilities, poor road networks and infrequent public vehicles. Constraints in financial resources were mentioned in all three counties.

Cataract surgery was also perceived to be costly because it required drugs which were not available in the hospital.

There were discussions on the importance of having a health facility close to the community to improve access to both health information and the facility.

One participant of a FGD explained their situation: *'When it comes to distance, it is very far because there are no readily available vehicles and there are no roads to pass, no vehicles until you look for motorbikes and even those ones cannot be found easily. So, it is hard.'*

Loss of productive time

Some patients did not take up the surgery because they were worried about the income they would lose while being in

hospital. For instance, in one of the FGDs, a woman had declined the surgery in Samburu because she feared she would lose her job and would not be able to buy food for her children. Similarly, another female patient, who had declined surgery in Turkana said; *"I'm the breadwinner of my family. If I go to hospital my family will have nothing to eat... I'll persevere with the pain in my eyes, rather than my children keep crying for food. Hunger kills."*

Some patients and CHVs in Laikipia County said that sometimes the timing of surgery camps was not suitable due to their farming activities, which required them to be present at the farm. As one CHV explained: *"Some people see it is a loss of time, especially if it is the planting season"*.

Insecurity

In all three counties, participants mentioned insecurity and hunger as factors affecting their decision about surgery. For example, some patients mentioned that they feared leaving their home because others could come and steal their livestock on which they were dependent. However, it was not clear whether this insecurity was a result of inter clan feuds or the lack of security agents in the communities.

Gender related factors

Some participants said that men were more likely to refuse surgery, because they felt they were responsible for their families and they didn't want to do anything that would make them immobile and prevent them from looking after their homes.

However, there were also participants who said that women were more likely to decline, particularly when their husbands also needed surgery. Women felt they had to look after their husbands, as one woman from a rural community explained: *“For me I said I will not be operated, so that I will be able to give him [my husband] drugs, ... I refused to be operated so that I could take care of him; I am the one who decided he will be operated first.”*

Programme/system level factors

The main themes identified here were i) waiting time and cancellations; ii) poor patient counselling; iii) poor post-surgery follow up; iv) numbers and skills of healthcare staff; v) attitudes and behaviours of healthcare staff; and vi) communication between healthcare teams.

Waiting time and cancellations

There were two waiting periods reported by study participants; a) waiting time between referral and travelling to the facility and b) waiting time between arrival at the facility and surgery.

A number of participants said that the screening camps were organised over a long period of time. This meant that patients referred for surgery had to wait to be transported to the hospital. Some patients would spend three days waiting for their surgery and some would give up.

Some patients had to wait at the facility because there were only a few surgeons and the teams were so busy, patients would often be left unattended for a long time, with some of them deciding to go back home. One female patient for example, explained how she was willing to be operated on, but could not receive her surgery after visiting the camp three times; the first time there were many people and she was turned away after the doctors operated on the sufficient number for that day (she had to go back home because she had left a young baby there). The second day the teams were choosing patients who were very old or frail, so she was left out. On the third day, she was seen by the team who dilated her eye, but then the time of the camp elapsed, and she was sent home.

In a number of cases, the camps were cancelled or rescheduled resulting in frustration of those patients who attended.

Poor patient counselling

Counselling was mentioned by both health care workers and patients; it would usually happen both before and after the surgery. However, for those who did not undergo the surgery, there was no information provided about their eye condition. Also, some patients were referred to the facility without any prior information about the surgery. Some patients said that they had been told about the surgery only when they boarded the vehicle, while others were only told that they needed surgery once they arrived at the facility. Many patients would get upset and refuse the surgery, as one patient explained: *“There was ... that I was told. He [health care worker] looked at it [my eye] and checked, checked ... said there “what do you see, what do you see” and I said I could not see. Then I was brought to be operated”*.

One patient mentioned that she had refused surgery because the consent form exonerated the surgeons from any malpractice: *“I refused because ... on top of that card they had written ‘If anything bad happens to your eyes after this operation, don’t come complaining about*

it’. So, I saw this and I was like, maybe this shows that these are not real doctors. That is how I refused...’

In some cases, study participants said that patients were forced to come to hospitals to undergo surgery, as one healthcare worker explained: *“Yes, they are there. We sometimes force them to come with us to the hospital.”* This in turn created more negative perceptions of surgeries and healthcare staff and led to more refusals within the community.

Poor post-operative follow up

Some patients and even CHVs reported that although the quality of care at the health facility was generally good, there were no follow up visits to monitor patients at home; and some patients who ended up with poor vision after the surgery attributed it to the poor follow up. Such patients felt they were abandoned by the facility staff, they spoke negatively about the surgery and spread fears in the community. A number of participants said that it was the role of health care workers to follow up with patients at home, because many patients could not move on their own and others were held up with family responsibilities. This however did not happen in practice. In the majority of cases, healthcare workers did not visit patients at home and some patients had not seen any healthcare staff since their

operation.

Number and skills of health care staff

One of the problems related to poor perception of surgery was inadequate numbers of healthcare staff, particularly in very busy camps, resulting in long waiting times and cancellations. For example, one of the HCWs reported that in some occasions, they lost patients who had gone through screening, pupil dilatation and signing the consent form because there was no one to look after them. Such patients would wait until they became impatient and then go back home.

Some participants said that the staffing problem also affected the pre-surgery counselling and post-surgery follow up. Busy and tired staff would have to sacrifice time for patient counselling and communication, which in turn led to misinformation and fears.

Although most study participants pointed out that the staff conducting the screening was adequately skilled and seemed to know what they were doing, in a few cases they did not have the right diagnostic skills and referred patients who did not require a surgery or could not be operated. In such cases, patients were diagnosed with cataract and referred for surgery, but when they went to the health facility, they were re-examined and told

that they did not qualify for surgery because their cataract was not advanced enough or because they had a different eye condition. In many cases such patients felt disappointed; they thought that the surgery was denied to them and discouraged others to attend the camp. In some cases, the problem of patients' misdiagnosis was due to staff shortages rather than staff skills.

Sometimes surgeries got cancelled because the surgeon had to be reassigned to other duties. In such cases, these patients also felt that the surgery was denied to them and they would spread negative rumors about the programme in their community.

Attitudes and behaviour of health care workers

Some patients and CHVs reported that in some instances, staff at the camps and health facilities were tired and had bad attitudes towards patients. It was explained that those patients who were welcomed and felt comfortable were more likely to accept the surgery. However, those who experienced bad attitudes were more likely to refuse the surgery or not to come back for a follow-up. Some patients also mentioned that some HCWs would not take time to listen to them but instead, would just write very fast and throw the card to the patient. Patients

also reported that some HCWs preferred to first see patients who were known to them, even when those patients would often arrive late and be further down in a queue. It was also mentioned that some young HCWs would spend time chatting or sending messages on their phones, while patients would be waiting in long queues. Such attitudes discouraged patients from coming back or advising others to go to the camp.

Communication between healthcare teams

Communication between CHVs and the facility staff during the screening campaign was also mentioned as a factor affecting the uptake of services. Timely communication about the surgery schedule enabled the CHVs to mobilise and sensitise patients on time. However, some CHVs reported that sometimes the communication campaign was delayed, and the mobilisation of patients was hurried, hence leaving some communities unreached. The villages covered by screening camps were large and the CHVs were strained to reach everyone in the time given. As a result, some patients missed their surgery date or could not attend due to clashes with other activities, such as farming.

Discussion

Poor uptake of cataract surgery has been reported previously in different settings (3, 10, 11). However, the rates of uptake and the reasons for refusals often vary depending on the patient characteristics and the organisation of cataract services.

This mixed method study aimed to assess the level of cataract surgery uptake in a community-based eye health programme where some of the known barriers to cataract surgery, such as user fees and transportation costs, have been removed.

Study findings provide some interesting insights into both the health seeking behaviour of patients living in the study sites, and the organisation of cataract services in these settings.

First, we could not establish the actual rate of uptake of cataract surgery in the two counties of Kenya where quantitative data were collected, as only 27.1 per cent of screening and surgery records could be linked. However, even if we assume that all patients recorded by the programme hospitals in these counties were patients referred by the camp, the uptake of surgery appears to be low. The rate is around 35 per cent, unless the records of a large proportion of patients

undertaking surgery in these facilities were not available at all, at the time of the study. The internal programme data collected by CATCH suggests that about 75– 80 per cent of patients, who had been offered a surgery, took it up. As this study collected data retrospectively using official facility records, the finding raises serious concerns about record keeping in the facilities included in this study. Poor quality of routinely collected health facility data is a well-known deficiency of health information management systems (HIMS) in most low income settings (12) and it appears that the problem could not be addressed by this programme.

Qualitative data from in depth interviews and FGDs reiterate the findings of other studies, which showed that barriers to uptake of cataract surgery are determined both by individual patients' characteristics including their culture, knowledge and beliefs, and programmatic / systemic level factors. An interesting insight from this specific study was the relationship between programmatic / systemic factors and individual patient perceptions and beliefs. For example, our findings explicitly show that a well-organised and appropriately managed service with positive attitudes of staff and good staff communication create positive views of a surgery in the community and increase

surgery uptake. On the other hand, busy, overcrowded and poorly managed camps and facilities, staffed with tired, overworked and unfriendly personnel, coupled with delays and cancellation of treatments, create negative attitudes and discourage patients from going for surgery. The findings of this study confirm propositions made in some recent health system research that it is not so much the limited number and poor distribution of health facilities that create barriers to access to healthcare, it is poor quality of care, limited expertise and negative staff attitudes in the facilities that exist that deter patients from seeking care (11, 13, 17).

Demand-side factors which arise from both individual and community characteristics, including cultural beliefs, individual fears, availability of social support, distance to the facility and other competing economic activities, are not new and have been reported in previous studies (10, 13, 18)

The lack of accurate information about cataract services and unmet patient expectations have also been documented (19, 22). It may be true that many donor-supported programmes, which are usually limited to 3 - 4 years of implementation, are not able to address these long standing cultural or social problems.

However, our study shows that service level factors, which are in control of such programmes, including numbers and training of staff, quality of services, quality of community mobilisation campaigns and communication between different teams are critical, and can either increase or significantly decrease demand for and uptake of surgery.

Like our study, supply-side barriers have been noted in a systematic study on uptake of obstetric care services at health facilities in Sub-Saharan Africa. These include: availability of services, geographical accessibility, affordability of services, staff interpersonal skills, human resources and content of counselling (23). In our study, health workers seemed to be aware that they needed to counsel the patients. However, adequate counseling was not offered in many cases. This could be attributed to the limited number of HCWs and very busy schedules of the camps. These findings are in line with a study in India that showed that counselling is a factor in increasing patient knowledge as well as resolving patient's decision conflict (24).

Although other studies have generated evidence to suggest that those with high literacy or employment were more likely to undergo cataract surgery (25), in this study the effect of these characteristics

was not explicit, possibly because this programme was implemented in trachoma areas, which are known to be some of the poorest areas in the countries with very large proportions of populations, who are illiterate and have no formal jobs.

The study also highlighted some known gender inequalities in cataract uptake (18). Although more women were identified and referred for cataract, the proportion of men among those operated was higher. Qualitative data also suggests that women tend to decline surgeries, particularly when their husbands require surgery too.

Our findings also confirm that user fees are a significant deterrent of cataract surgery uptake and had we not provided free surgery and transportation in this programme; the number of refusals would have been much higher. However, the study also suggests that patient cost elimination itself is not an ultimate solution, as the perceived quality of care remains an important deciding factor.

Our research has several programme implications as follows:

1. Large scale cataract programmes require significant numbers of staff to avoid staff shortages and burnout; staff should be

- appropriately trained and regularly supervised;
2. Community mobilisation campaigns need to be well planned and have enough time to sensitise communities;
 3. Information about surgery needs to be comprehensive and preferably standardised to ensure all staff, who interact with potential patients at the community, camp or facility level, has this information at hand and is trained to use it. Culturally appropriate information packages will need to be translated into local language and should be available to all providers. This should include the details of pros and cons, duration of surgery, responsibilities of patients, as well as care givers, and make clear the pre- and post-surgery instructions to patients. Clear communication for patients who cannot be operated on should also be included.
 4. Patient counselling should be given adequate time within the treatment protocols and pathways of care.
 5. Programmes should assess potential bottlenecks in the programme delivery and put in place mitigating factors. Particular attention should be given to engagement with CHVs and other community teams. Communication between different teams, appropriate planning of camp and surgery schedules, is critical to avoid delays and cancellations.
 6. Programmes need to identify patients who are at risk of drop out; e.g. single women, very old patients, those who live on their own or have specific cultural or religious beliefs; and develop targeted strategies to improve their access to services. There is a need for better understanding of such subgroups and what drives their decisions.
 7. Engagement with patient champions who can promote positive attitudes to surgery should be systematically supported; including training, support and motivation of such patients.
 8. There is a need to put in place better follow up mechanisms after surgery, especially for the elderly or disabled who may have difficulty returning to the hospitals for reviews.

9. Programmes need to ensure proper systems are put in place for improving quality of patient data collected at the camp and facility levels and find technological

solutions for linkages between these datasets.

References

1. Bourne RRA, Flaxman SR, Braithwaite T, Cicinelli MV, Das A, Jonas JB, et al. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta analysis. *The Lancet Global Health*. 2017;5(9):e888 e97.
2. WHO. Blindness and vision impairment 2018 [updated 11 October 2018; cited 2018 29th November]. Available from: <http://www.who.int/en/news room/factsheets/detail/blindness and visual impairment>.
3. Aboobaker S, Courtright P. Barriers to Cataract Surgery in Africa: A Systematic Review. *Middle East African journal of ophthalmology*. 2016;23(1):145 9.
4. WHO. Universal eye health: A global action plan 2014–2019. Geneva: World Health Organization; 2013.
5. Miteniece E, Pavlova M, Shengelia L, Rechel B, Groot W. Barriers to accessing adequate maternal care in Georgia: a qualitative study. *BMC Health Serv Res*. 2018;18(1):631.
6. Afolabi MO, Daropale VO, Irinoye AI, Adegoke AA. Health seeking behaviour and student perception of health care services in a university community in Nigeria per cent *J Health*. 2013;Vol.05No.05:8.
7. Sara M. A review of health seeking behaviour: problems and prospects. *Health Systems Development Programme*. University of Manchester; 2003.
8. Thaddeus S, Maine D. Too far to walk: maternal mortality in context. *Social science & medicine* (1982). 1994;38(8):1091 110.
9. Briesen S, Geneau R, Roberts H, Opiyo J, Courtright P. Understanding why patients with cataract refuse free surgery: the influence of rumours in Kenya. *Tropical medicine & international health : TM & IH*. 2010;15(5):534 9.
10. Briesen S, Geneau R, Roberts H, Opiyo J, Courtright PJTM, Health I. Understanding why patients with cataract refuse free surgery: the influence of rumours in Kenya. 2010;15(5):534 9.
11. Mitsuhiro MH, Berezovsky A, Belfort R, Jr., Ellwein LB, Salomao SR. Uptake, Barriers and Outcomes in the Follow up of Patients Referred for Free of Cost Cataract Surgery in the Sao Paulo

- Eye Study. *Ophthalmic Epidemiol.* 2015;22(4):253 9.
12. Kihuba E, Gathara D, Mwinga S, Mulaku M, Kosgei R, Mogoia W, et al. Assessing the ability of health information systems in hospitals to support evidence informed decisions in Kenya. *Glob Health Action.* 2014;7:24859 .
 13. Ajibode H, Jagun O, Bodunde O, Fakolujo V. Assessment of barriers to surgical ophthalmic care in South Western Nigeria. *Journal of the West African College of Surgeons.* 2012;2(4):38 50.
 14. Ayeni E, Bekibele C, Baiyeroju AJNJoO. Service uptake in UCH, Ibadan: a time flow study. 2005;13(2):49 53.
 15. Lewis C, Abrams K, Seervai S. Listening to low income patients: obstacles to the care we need, when we need it. 2017.
 16. Liu T, Ong EL, Yan X, Guo X, He M, Friedman D, et al. Factors influencing the success of rural cataract surgery programs in China: the study of hospital administration and relative productivity (SHARP). *Invest Ophthalmol Vis Sci.* 2013;54(1):266 73.
 17. Newman Casey PA, Ravilla S, Haripriya A, Palanichamy V, Pillai M, Balakrishnan V, et al. The Effect of Counseling on Cataract Patient Knowledge, Decisional Conflict, and Satisfaction. *Ophthalmic Epidemiol.* 2015;22(6):387 93.
 18. Sakara A, Namooq MY, Badu Nyarko SK. Misconceptions And Rumours About Family Planning Among Moslem Males In Tamle Metropolis, Ghana. 2014.
 19. Dhaliwal U, Gupta SK. Barriers to the uptake of cataract surgery in patients presenting to a hospital. *Indian J Ophthalmol.* 2007;55(2):133 6.
 20. Syed A, Polack S, Eusebio C, Mathenge W, Wadud Z, Mamunur AK, et al. Predictors of attendance and barriers to cataract surgery in Kenya, Bangladesh and the Philippines. *Disability and rehabilitation.* 2013;35(19):1660 7.
 21. Xu Y, He J, Lin S, Zhang B, Zhu J, Resnikoff S, et al. General analysis of factors influencing cataract surgery practice in Shanghai residents. 2018;18(1):102.



22. Zhang XJ, Jhanji V, Leung CK, Li EY, Liu Y, Zheng C, et al. Barriers for poor cataract surgery uptake among patients with operable cataract in a program of outreach screening and low cost surgery in rural China. *Ophthalmic Epidemiol.* 2014;21(3):153-60.
23. Kyei Nimakoh M, Carolan Olah M, McCann TV. Access barriers to obstetric care at health facilities in sub-Saharan Africa: a systematic review. *Systematic reviews.* 2017;6(1):110.
24. Newman Casey PA, Ravilla S, Haripriya A, Palanichamy V, Pillai M, Balakrishnan V, et al. The Effect of Counseling on Cataract Patient Knowledge, Decisional Conflict, and Satisfaction. *Ophthalmic epidemiology.* 2015;22(6):387-93.
25. Syed A, Polack S, Eusebio C, Mathenge W, Wadud Z, Mamunur A, et al. Predictors of attendance and barriers to cataract surgery in Kenya, Bangladesh and the Philippines. *Disability and rehabilitation.* 2013;35(19):1660-7.



We work with partners in low and middle income countries to eliminate avoidable blindness and promote equal opportunities for people with disabilities.

www.sightsavers.org