



©Sightsavers 2017

Cataract Surgery Uptake in Zambia

2019



Authors:

Eunice Mailu¹; Stevens Bechange²; Titamenji Chulu³; Glenda Mulenga³; Emma Jolley⁴ & Elena Schmidt⁴

From ¹Sightsavers Kenya; ²Sightsavers Uganda; ³Sightsavers Zambia and ⁴Sightsavers United Kingdom.

Acknowledgments

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

- Study respondents, who invested their time and provided information for the study
- the National Health Research Authority and health facility managers in Monze, Kalomo and Choma for their guidance and support
- Sightsavers country office in Zambia for their organisational and logistical support with special thanks to Mr. Francis Kalusa and Ms Thandiwe Phiri
- Sightsavers global teams for their overall technical assistance, specifically Ms Effie Rarite, Ms Ziporah Mugwang'a, Mr Moses Chege and Dr Tesfaye Adera
- Dr Mary Nyikuri for assistance with data analysis.

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

Cataract Surgery Uptake in Zambia	1
Acknowledgments	2
Table of Contents	3
List of Tables	3
Acronyms and Abbreviations	4
Summary	5
Introduction	7
Methodology	10
Study design and sampling	10
Data collection.....	10
Data management and analysis	10
Ethical considerations	10
Results	11
Quantitative findings.....	11
Qualitative Findings.....	13
Factors influencing cataract surgery uptake.....	14
Discussion	22
References	25

List of Tables

Table 1: Characteristics of patients who were screened, found with operable cataract and referred for surgery	11
Table 2: Uptake of Cataract Surgery (based on available records)	12
Table 3: Uptake of cataract surgery stratified by demographic characteristics of patients (based on 127 records that could be linked between screening and surgery registers)	12
Table 4: Number of interviews and Group discussions conducted per region	13

Acronyms and Abbreviations

CATCH	Co-ordinated Approach to Community Healthy eyes
CHA	Community Health Assistant
CHWs	Community Health Workers
FGDs	Focus Group Discussions
HCWs	Health Care Workers
IAPB	International Agency for the Prevention of Blindness
IDI	In depth Interviews
OCOs	Ophthalmic clinical officers
ONs	Ophthalmic nurses
REC	Research Ethics Committee
WHO	World Health Organization

Summary

Background: Cataract remains the leading cause of blindness in middle- and low-income countries and in Africa, cataract contributes to approximately half of all causes of blindness. Eye conditions in Zambia are ranked seventh among the main causes of hospital admissions and account for 31% of all out-patient visits at public facilities. The prevalence of blindness in Zambia is estimated at 1.1% in the general population and 2.8% in people aged 50 years and above with cataract being the leading cause. This study sought to understand demand for cataract surgery and investigate the programme/health system, community and individual factors that influence cataract surgery uptake in the context of a programme that eliminated some of the known barriers to cataract surgery.

Methods: The study was integrated within a four-year intervention programme, called Coordinated Approach to Community Healthy Eyes (CATCH). The programme was funded by the UK Department for International Development and implemented by Sightsavers and their partners in five African countries (Kenya, Uganda, Zambia, Mozambique and Malawi) with the aim to improve access to eye health services and reduce the burden of avoidable blindness among people living in trachoma endemic areas. The study deployed a mixed method design and combined quantitative and qualitative data collection approaches. Quantitative data was abstracted from screening and surgery registers for all patients who had been identified and referred for cataract surgery under the CATCH programme in Kalomo, Choma and Monze districts between July 2016 to June 2017. Qualitative data was collected across two districts (Kalomo and Monze) using in-depth interviews and focus group discussions with purposively selected patients, health care providers and community leaders.

Results: Out of the 517 patients who were screened and referred for surgery in the study period, the records of surgery were available for 25% (127) of patients. The total number of patients operated in the study districts in the same period was 353, 127 of them being recorded, as referred by CATCH. The most likely explanation of this discrepancy is the gap in documentation at the hospital level with patients operated recorded under different names and addresses than those at the screening camps. Due to this discrepancy the study could not estimate the actual rate of uptake of surgery in these regions. However, even if we assume that all 353 patients operated in the study period were referrals from CATCH, the uptake of surgery in these districts was 68%. Qualitative data shows that several individual, community and programme/health system factors have influenced patients' decisions about surgery with experiences of previously operated patients being one of the most critical factors. Other factors identified included: cultural beliefs about eye health, misinformation and rumors about surgery, distance to health facility, availability of social support and other competing life priorities. The study provides some interesting insights into a relationship between programme/system level factors and patient individual perceptions and beliefs. It shows that a well organised and appropriately managed system with positive attitudes of staff and good staff communication create 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 3-4-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 good communication between different healthcare teams. These factors are equally important and can either increase or significantly decrease demand for and uptake of cataract surgery. The study has a number of programme implications and suggests that large scale cataract programmes, such as CATCH should be planned and designed through the health system strengthening lens, i.e. identifying strengths and weaknesses of the health system, within which the programme is being designed and considering how the risks arising from the system weaknesses can be minimised and how specific system components can be strengthened to maximise the effectiveness and efficiency of the cataract programme.

Introduction

The Global Burden of Diseases (GBD) study of 2017 estimated that 1.3 billion people live with some form of vision impairment worldwide, of whom 188.5 million 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). 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.

Ocular morbidities are serious public health issue in Zambia. Eye infections are ranked seventh among the main causes of hospital admissions and account for 31% of all out-patient visits at public facilities in the country (4). The prevalence of blindness in Zambia is estimated at 1.1% in the general population and 2.8% in people aged 50 years and above with cataract being the leading cause (5).

Access to cataract surgery is a key priority identified in the World Health Organisation (WHO) Global Action Plan. However in many developing countries, multiple barriers on both the demand and supply of care prevent patients from accessing surgery (3, 6).

On the demand side, patient health seeking behaviour determines the uptake of surgery and is influenced by multiple factors, including patients' knowledge of a health issue, their perception of risk, social and cultural norms and characteristics of health services (7). Therefore the success of any health intervention depends on a good understanding of factors influencing patients' health seeking behaviour and their acceptability of services (8).

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 a range of geographical, social, economic, cultural and organisational factors, all of which can act as either barriers or facilitators of the service uptake (9). 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 (10). A recent systematic review of studies of eye health seeking behaviour in Africa showed that a range of factors, including individual socio-economic characteristics, geographical location, social and cultural norms and the organisation of health services, influence the uptake of cataract surgery (3).

A number of earlier studies suggested that user fees and transport costs are a significant barrier to the uptake of cataract surgery. However, evidence also suggests that even in the contexts, where the impact of these barriers is minimised through providing free surgeries 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 (11). 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 eye health seeking behaviour in Zambia and contribute to the evidence base on the uptake of cataract surgeries in Africa. The study was implemented within an eye care programme, where the surgeries were 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 maximise the surgery uptake and efficiency of services in Zambia and similar healthcare settings.

The CATCH Programme

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 and 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 the burden of 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 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 Zambia, the CATCH programme was implemented in 10 districts in Southern Province; Chikankata, Mazabuka, Monze, Kalomo, Zimba, Gwembe, Kazungula, Choma, Pemba and Namwala, where trachoma was endemic. The study was conducted in three districts (Kalomo, Monze and Choma) with the highest number of surgical camps.

Although the CATCH programme followed broadly the same model of service delivery across the Province, there were a number of differences between the districts. In Monze, patient mobilization was done through the use of radio messaging (Chikuni radio), community health workers (CHWs) and community health assistants (CHAs). The heads of the local health centre were given information about the programme and a schedule of screenings. They passed this information to the CHWs attached to their centre, who in turn notified the communities about the upcoming screening. This approach helped to ensure that community members seeking eye care from the health centre received the correct information. Monze used two screening set ups i.e. i) screening followed by surgeries scheduled for the following week and ii) screening followed by immediate pick up and transportation of patients to the hospital, using programme or health facility vehicles. Patient pickup was at the camp with a few exemptions for very old patients with significant mobility limitations, who were picked up from their homes by CHWs.

In Kalomo, Namwianga Mission clinic received patients referred from the screening camps. Patient mobilisation was done using two community radio stations (Macha and Namwianga). Screening of patients was done several weeks ahead of the camp and the surgeries were organised the week following the camp. Transportation of patients was organised using a bus or a truck of Namwianga Mission clinic. These vehicles of a larger capacity allowed for a higher coverage of this very large district to make sure that all referred patients could be picked up.

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, i.e. user fees and transport.

Objectives

The specific objectives of the study were as follows:

1. To characterise the level of cataract surgery uptake in selected districts covered by the CATCH project.
2. To explore individual, community and programme level factors that influenced the uptake of cataract surgery in these settings.
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 cross sectional mixed methods 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 01, 2016 and June 30, 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). Qualitative data were collected in Monze and Kalomo districts only.

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 thematic 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

An ethical approval was obtained from the University of Zambia Biomedical research ethics committee. A permission to carry out the study was also obtained from National Health Research Authority. Information about the study, its purpose and the use of data was provided to all respondents in their preferred language. All participation was voluntary, and participants could withdraw their consent at any time. Written informed consents were obtained from all study participants involved in the qualitative component of the study.

Results

Quantitative findings

The records obtained from the programme show that in total, 517 patients were diagnosed with cataract and referred for cataract surgery through the CATCH programme in the three study districts in the evaluation period. The majority of referrals were from Monze (44%) and Choma (41%) districts.

The majority of patients referred for cataract surgery were aged 60+ years (87.5% in Choma, 83.3% in Kalomo and 82.7% in Monze). The proportion of women among the referred patients was close to 55% in Kaloma and Monze and just over 51% in Choma (Table 1).

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

Stratification of the Screened population by Gender and Age group						
	30-60		60+		<30	
Gender	N = 65	%	N = 436	%	N = 13	%
Female	33	(50.8)	239	(54.8)	2	(15.4)
Male	32	(49.2)	197	(45.2)	11	(84.6)
Stratification of the Screened population by Region and Gender						
	Choma		Kalomo		Monze	
Gender	N = 216	%	N = 72	%	N = 229	%
Female	111	(51.4)	40	(55.6)	125	(54.6)
Male	105	(48.6)	32	(44.4)	104	(45.4)
Stratification of the screened population by Region and Age group						
	Choma		Kalomo		Monze	
Age grp	N = 216	%	N = 72	%	N = 226	%
30-60	22	(10.2)	6	(8.3)	37	(16.4)
60+	189	(87.5)	60	(83.3)	187	(82.7)
<30	5	(2.3)	6	(8.3)	2	(0.9)

Records of surgery were available for 127 (25%) patients referred through the CATCH camps. However, the hospital surgery registers show that in the evaluation period a total of 353 patients were operated on for cataract with 127 of them being referred by CATCH. This suggests that either 226 of the operated patients were walk ins or there was a mismatch of screening and surgery records and a large number of referred patients did attend the surgery but were recorded under different names or addresses, and therefore could not be linked to the screening records. The percentage of records that could be linked was highest in Kalomo (40/72, 55.6%). In Choma it was 26.9% (58/216), while in Monze only 12.8% of records (29/226) could be linked.

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

Uptake of surgery among the screened		
Surgery uptake	No. Screened	Percent
No	390	75%
Yes	127	25%
Total screened and referred	517	
Uptake of surgery by screening status		
Screened	Number of surgeries	Percent
No (Suspected walk-ins) ^a	226	64%
Yes	127	36%
Total that took up surgery	353	

^a**Suspected walk ins** are those who took up surgery and were not in the screening register

If we assume that all 353 patients operated for cataract in the study period were referrals from CATCH, the uptake of cataract surgery in these districts was 68.3%. This figure however should be treated with caution, as it is highly likely that some of these 353 patients were walk ins.

Among 353 patients operated at the district facilities in the study period, data on sex was available for 337 patients and data on age was available for 318 patients. With regards to patient characteristics, those operated for cataract were broadly similar to those diagnosed with cataract at the CATCH camps, although the proportion of women and older patients among those operated, seems to be slightly lower than among those referred (51.9% vs 53.4% for women and 82.4% vs 84.3%) (Table 3). We do not know whether these differences are due to the problems with record keeping and accuracy of data on patient age and sex, or the uptake of surgery is truly slightly lower among women and older patients.

Table 3: Characteristics of patients operated for cataract (based on 127 linked records and all operated for cataract)

	Total Operated		Uptake of Surgery (based on linked records)	
	N	(%)	N	(%)
Sex				
Male	162	(48.1)	60	(47.2)
Female	175	(51.9)	67	(52.8)
Total	337		127	
Region				
Kalomo	67	(19)	40	(31.5)
Monze	132	(37.4)	29	(22.8)
Choma	154	(43.6)	58	(45.7)
Total	353		127	

	Total Operated		Uptake of Surgery (based on linked records)	
			Linked records	
Age Group				
<30	15	(4.7)	2	(1.6)
30-60	41	(12.9)	12	(9.4)
60+	262	(82.4)	113	(89.0)
Total	318		127	

Qualitative Findings

To collect qualitative data; 4 and 13 FGDs were conducted in Kalomo and Monze respectively, while the number of individual in-depth interviews was 26, and 25 respectively (Table 4).

Table 4: Number of interviews and focus group discussions conducted per district

	Kalomo	Monze	Total
Category of Interview	IDIs		
Female Patients Operated	0	2	2
Female patients not Operated	2	5	7
Male Patients Operated	7	3	10
Male patients not Operated	0	2	2
Community Leaders & CHWs	12	9	21
Health Care Workers (OCOs and ONs)	5	4	9
Total In-depth interviews	26	25	51
	FGDs		
Female Patients Operated	0	1	1
Female patients not Operated	0	0	0
Male Patients Operated	0	2	2
Male patients not Operated	0	0	0
Male Patients operated and not Operated	1	3	4
Males and Females patients operated	2	2	4
Female patients operated and not operated	1	1	2
Community Leaders & CHWs	0	4	4
Total Focus Group Discussions	4	13	17
Total Interviews (Both FGDs and IDI)	30	38	68

Factors influencing cataract surgery uptake

For the purpose of this study factors affecting patients' decisions about the surgery have been broadly organized 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 factors

There were three main reasons given by the patients, who undertook cataract surgery explaining why they agreed to the operation: i) improvements in livelihoods and ability to support the family ii) positive experiences of others and iii) encouragement of the family.

Improvements in livelihoods and ability to support the family

A number of patients said that they had accepted the cataract surgery because they wanted to have their sight restored and get back control of their lives. The fear of losing one's livelihood and dependence on others were among the patients' key considerations. Some felt that if they don't go for surgery, they would end up blind and would not be able to perform their daily chores. Several patients reported that they were the providers of their family and if they were to go blind, their families would have challenges to survive. This is how one female patient explained her reasons for the surgery:

'If I get blind here, it will mean that my children would not go to school, I can fail to feed them, clothing and other necessary things would be impossible to do....'

A male patient from Monze expressed similar reasons but went even further saying that for him, *"being blind was like being dead."*

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 them in their decision about the surgery. In a focus group discussion of female rural patients from Monze, participants gave examples of people in the community who had been blind but could see after the operation. Patients, who knew someone who had undergone surgery with good vision outcomes, felt encouraged and motivated. CHWs also reported that previously operated patients were often used as community champions and their involvement helped to improve the uptake of surgery by others.

Encouragement of the family

Family support played an important role in the decision-making process. Several patients who had been operated on, talked about their family support in terms of encouragement, accompanying them to the hospital and providing care after the surgery. Healthcare workers interviewed also talked about family support as a key influencing factor, particularly for patients who were old and had to be escorted from the screening camp and to the hospital.

Programme or health system level factors

When asked about the programme or health system factors that encouraged patients to take up surgery, respondents spoke mainly about two main reasons: 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 accept the surgery was the provision of free surgery, medicines, transportation and food. Patients said that they were willing to go to the hospital because the surgery and the medicines were free. Even when patients finished their first batch of medicines and returned to the facility for a post-operative review, they were given additional medicines for free. Many patients were also happy about free transport and food provided at the facility. Patients were taken to the hospital and brought back to their communities, which saved them a lot of time. A number of patients also said that if there were no food and transport provided to them, they would not have turned up for surgery, as they had no money to pay for transport or buy food, as one male patient explained:

‘Transport, we say thank you. From my side, I would not have gone to Namiyanga for I would have not managed to raise money for transport’.

Positive attitudes of healthcare staff

Most patients reported that they were received at the facility by polite and attentive staff, who provided them with good care. Many mentioned that they were treated with respect, including private situations, such as when getting ready for bed.

It was further mentioned that the drivers deployed by the programme were professional and respectful; they helped patients to board the vehicle and made them comfortable during their journey. Patients appreciated that the drivers were aware that they were carrying old persons; they did not drive recklessly and ensured that all patients had their safety belts on. One patient mentioned that the driver drove so well that he could not feel the bumps that were on the road. These little gestures motivated patients and made them talk positively about the programme.

Surgery Barriers

Individual and community level barriers

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

Cultural beliefs and perceptions of eye problems

Healthcare workers and community leaders referred to various cultural beliefs and myths about eye issues in the study communities. For example, some patients believed that cataract was an inherited condition and therefore nothing could be done about it. There was also a belief that poor sight was natural for old people and since old people were not economically active, there was no need to restore their sight.

There were also those, who believed that eye problems were related to witchcraft. One patient for example, said that his community believed that people go blind when they see a woman giving birth. Such patients preferred to see witchcraft doctors or use traditional remedies. One blind boy in Monze, said that his mother believed that eye problems were seasonal and could be cured with the sprouting of certain trees. Others reported using a traditional drink called *bwantu*. These patients did not want to travel too far from their home, as they did not want to miss on their regular drink.

Fear of and rumours about cataract surgery

There were also negative perceptions of and rumours about cataract surgery. Some people believed that people could go blind after the surgery. This was particularly common in the villages where someone had undergone the surgery and their vision had worsened. For example, in one of the FGDs, two female patients said that they had declined the surgery because they heard that people lose sight after the surgery. They also feared staying in the house alone for two or three months because they heard about someone in their community, who had to stay indoors for three months after the surgery. This is how a female patient from Monze expressed her fears:

'I fear to be operated because I have seen many of them who were operated. Their eyes are damaged and shading tears, they are in the houses. I was even thinking. Is there no other way apart from the surgery?'

A female patient from Kalomo expressed similar concerns and said:

'...because it is painful and sometimes you can lose your eyes for good.'

Some patients believed that during the surgery the eyes get removed; some believed that the human eyes get replaced with the eyes of a goat. In some communities, patients were also scared of travelling in vehicles; they feared that they would get involved in an accident and die. One patient for example said that he would rather *'have his eyes dead'* than die in an accident on the way to hospital.

Lack of social support

There were three main types of social support patients were looking for when referred for surgery: a family member or a neighbour to go with to the hospital; someone to watch over their home, while they were away; and a relative or a friend to take care of them after the surgery. Those who did not have anyone to provide this kind of social support, tended to decline cataract surgery. For example, a female patient from Kalomo explained why she had declined surgery:

'Yes, there I had challenges because [I] thought of who would nurse me after the surgery, who could be cooking for me since you say smoke and surgery are enemies. So being in the house for two months, I would not have managed it, dear.'

Distance and transport costs

A number of patients said that the lack of money to pay for transport to go to the hospital was their major concern. This challenge was mentioned in the FGDs in both Kalomo and Monze. In Monze, patients said that to raise money to go to hospitals they would have to sell

groundnuts, chicken or even a goat. The CHWs also said that they knew patients who had severe visual impairment but would not go to hospital because of poor financial circumstances. Both patients and CHWs talked about significant costs associated with the surgery, including transport for the patient and someone to accompany them, costs of medicines and costs of food, while at the hospital and after being discharged. Although some patients knew that the hospitals would provide them with food, they thought it may not be sufficient and they would have to buy extra food. Some patients were concerned that the food at the hospital may be given only to them and not to their relative accompanying them.

A number of patients in this study mentioned that surgery was not for them because they lived in poverty and could only go to nearby health centers. Bigger hospitals located in other towns were 15 to 40 kilometers away and they could not walk there and could not afford paying for transport. Overall, it seems that many patients referred for cataract surgery in this project had little information about what to expect from the hospital and which services were free. It also seems that many patients based their decision on their general beliefs about hospital care, rather than information about the care provided in this programme.

Some healthcare workers in Monze also mentioned that transport was a challenge for patients, which affected their outreach and follow up activities. It however remained unclear whether this challenge was specific to Monze or whether transport support was irregular across different camps supported by the programme.

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 example, in one of the FGDs in Monze, a male patient expressed his concerns about losing his income and being uncertain about the surgery outcomes:

‘So, the time you have to spend going to the hospital could have been spent doing other things at home. Now, because of the problems with your eyes, you just go. Yet you are not sure if you are even going to get better. So, time get wasted on the things you are not sure of.’

In some instances, people did not have enough information or were misinformed about how long they would stay in the hospital or at home, and when they could return to their normal routines and economic activities. As one patient explained:

‘The conditions attached after the surgery do not favour us to work for money. But we need money for survival’.

CHWs also mentioned that sometimes the timing of the surgery camps was not suitable and coincided with the farming activities, which is a very busy period for many families. As a result, a number of patients refused surgeries because either they or their relatives were busy at the farm:

‘Because sometimes ... the person who escorts may be as well busy. They may say to the patient: Just hold on a bit so that I plant while the dew is still on the ground.’

Programme or system level barriers

The main themes identified under this theme were i) waiting time; ii) poor patient counselling; iii) poor communication between health care teams; iv) poor post-surgery follow up; v) numbers and skills of healthcare staff; vi) attitudes and behaviours of healthcare staff; and vii) limited working space and equipment.

Waiting time

Both healthcare workers and patients talked about waiting time at both the screening camps and surgical facilities. In the areas where there was a long waiting period between the camp and the actual surgery, many patients would change their mind and refuse to go to surgery. In some cases, this would happen because patients spoke to a traditional healer or someone with bad experiences of surgery. Sometimes, it could be because of a patient's personal circumstances or the availability of someone to go with them to the hospital would change.

Some patients also said that they had to wait for a long time at the hospital. In a few cases, patients reported waiting for up to 3 days. In such situations, a number of patients gave up on surgery and left the facility, as one male participant explained:

'At times, you come early, before they open the facility; but you will be made to wait and sometimes, you go back home without being treated; the nurse knocks off even before time.'

Several patients and CHWs also talked about situations where patients would be waiting for a camp, but the camp dates would change, and no one would inform them. Many would come to the camp and would be waiting without anyone to attend to them:

'What happened last year, they made an appointment to come at 08:00 ... to Hamapande; people gathered in numbers and we kept waiting. Did they even come that day? They never came; we just dispersed, and people did not eat anything. and this affected them so much.'

Poor patient counselling

Counselling was mentioned by HCWs, CHWs and patients. It was explained that the duration of the counselling and the quality of information given to the patient during the counselling were very important in helping patients to make a decision about the surgery. However, in many camps and facilities, a comprehensive counselling was not possible. One CHW for example said that the time allocated to the counselling at his facility was very short; the facility was very busy and there were long queues of patients waiting for an appointment. Although HCWs tried to counsel the patients, the sessions were reduced to the minimum; HCWs were in a hurry and there was no time to adequately address patients' questions or concerns.

Many patients also believed that they did not have sufficient pre-operative counselling. Some patients even said that they felt they were forced to agree to take up the surgery and no one explained to them what would happen in the hospital or how long the surgery would last. Such patients tended to go back to their villages and spread negative rumours about the surgery. They would say that they were forced to undergo the surgery and discouraged their neighbours to go to the screening camp.

Furthermore, a number of CHWs and patients said that the information given to the patients discharged from the hospital was limited and unclear. Many patients were confused about the post-operative care they need. Some patients for example were told to stay in the house for more than a month. This was not practical and discouraged other patients to take up surgery.

Healthcare workers said that they lacked training in counselling and many facilities did not have dedicated counselling staff.

Poor communication between healthcare teams

Communication between CHWs and facility staff during the screening campaign was also mentioned as a factor affecting the uptake of surgeries. Timely communication was reported to be particularly important for effective sensitisation and mobilisation campaigns. However, several CHWs said that often the communication about the upcoming camps was delayed and the mobilisation of patients was hurried. This is how one CHW explained what happened in their district:

'Mobilisation was not given enough time, ... many people were not attended to. Sightsavers just made phone calls that they will be coming, and we didn't have enough time to tell people about it.'

Poor or delayed communication was particularly bad for large villages, where CHWs struggled to reach everyone in the short time given. As a result, some patients from these villages were missed on the surgery date.

In some instances, screening camps were postponed or reallocated to another village but the CHWs and the patients were not informed, or they missed information announced on the radio. Those who would turn up to the cancelled camps felt disappointed and would not attend another camp, as one patient explained:

'I went to that place twice. The first day, I was told to return on Thursday, that is when we were told to come with two plates, a cup and a spoon. Then we went, that's when I found, they said we were supposed to come in the beginning [of the week] - Sunday, Monday, Tuesday, and Wednesday. Thursday was the final day. They changed the day, the day we were told to come was Thursday but somehow it was the day they were finishing. So, they didn't attend to me because they had started from Sunday. They announced on the radio on the change of days, but we didn't hear that information. So, when we came on Thursday, we found they had finished.'

Poor post-surgery follow up

The lack of follow up after the surgery was also mentioned as a factor affecting patients' perception of surgeries. Some patients said that they had seen patients after the surgery who suffered and received no help; such patients would often end up with poor vision and others in the village would believe that this was because of the lack of follow up. Some patients wanted surgical teams to provide care in their nearby facilities, because they did not want to travel back to hospital, but in most cases, this was not possible. HCWs from the hospitals said that sometimes they would agree to provide follow up visits to the nearby

primary care clinics. However, they themselves did not have any transport to travel to these clinics. In these situations, patients would turn up to primary care clinics for a review, only to find out that there were no doctors to examine them or give them additional medicines. This caused frustration among both patients and healthcare workers.

Another problem with follow up reviews mentioned by several CHWs was the lack of medicines at the health facilities. Respondents explained that on several occasions, patients would come to the hospital to refill their medicines, but the hospital would run out of medicines and ask patient to come again. Given long distances and travel time, these situations were disappointing and frustrating for many patients.

Numbers and skills of healthcare staff

One of the problems affecting the quality of care was inadequate numbers of healthcare staff, particularly in large districts and at very busy camps, resulting in long waiting times and cancellations. For example, one HCW reported that on several occasions, they lost patients who had undergone screening and pupil dilatation and signed the consent form because there was no staff to attend to them. Such patients would wait for a long time until they got impatient; they would eventually go home and never come back. Staff shortages also affected both the pre-operative counselling and the post-operative follow up. Large districts, such as Kalomo were very problematic because they had limited staff to cover large areas leading to a very high workload.

Furthermore, the areas, where the programme took place did not have any surgical teams at the local facilities. The areas would often rely on just one surgeon based at the provincial hospital. The surgeon would have many competing priorities and many patients would have to wait at the surgical facility for a very long time. In some cases, the surgeon would be re-assigned to other duties and the surgeries would be cancelled leaving many patients unhappy and disappointed.

Finally, although most study participants noted that the staff conducting the screening were adequately skilled, there were a few cases, when patients were misdiagnosed and referred for surgery incorrectly. When such patients went to the health facility, they were re-examined and told that they did not qualify for surgery because their cataract was not mature or because they had another eye condition. In such cases, patients were disappointed and thought that the surgery was denied to them.

Attitudes and behaviours of healthcare staff

Some patients and CHWs reported that in some instances staff at the camps and health facilities were tired and treated patients badly. Those who experienced bad attitudes, disrespect or neglect were more likely to refuse the surgery or not to come back for a follow up. Some patients also said that some HCWs would only treat well those patients they knew personally and would show no attention to others. Some patients complained about personal phone calls made by HCWs during their examination:

‘Sometimes, they have already started lighting you with their small torch they use; then the phone rings and they start answering their phone. Sometimes, it’s not even a phone call, they are just pressing ... checking these things, which came nowadays WhatsApp.’

Limited working space and equipment

The issue of limited space and surgical capacity was raised by healthcare workers in Monze. They said that lower level health facilities did not have capacity to conduct complex surgeries, for example, paediatric surgeries. Patients also said that these facilities did not have enough space to handle large numbers of patients booked for surgeries leading to some patients waiting outside, where it was windy and cold. Some facilities did not have sufficient space in the surgical wards.

Discussion

Poor uptake of cataract surgeries has been reported previously in different settings (3, 12, 13). 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 health seeking behaviour of patients living in the study sites and organisation of cataract services in these settings. First, we could not establish the actual rate of uptake of cataract surgery in the study districts, as only 25% of screening and surgery records could be linked. The internal programme data collected by CATCH suggests that about 75% - 80% of patients, who had been offered a surgery, took it up. As this study collected data retrospectively using official facility records, we can neither confirm nor disprove these figures. There was a significant number of patients screened at the camp and a significant number of patients operated. The most likely explanation of this discrepancy is the gap in documentation, particularly at the hospital level with patients operated recorded under different names and addresses than those at the screening camps. Poor quality of routinely collected health facility data is a well-known deficiency of health information management systems (HIMS) in most low-income settings (14). However, even if we assume that all patients recorded as operated were referral from the camp, the uptake of referrals in this period was only 68%, suggesting that a large proportion of patients in this setting decline the surgery, even when the surgery and transport to the health facility is provided for free.

Qualitative data from in-depth interviews and FGDs reiterate this suggestion and show that there are many individual, community and system level factors contributing to patients' health seeking behaviour. An interesting insight from this specific study was a relationship between programme or system level factors and patient individual perceptions and beliefs about care. For example, our findings explicitly show that a well-organised and appropriately managed system 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 (13, 15-19).

Demand side factors which arise from both individual and community characteristics, including cultural beliefs about eye problems, 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 (12, 15, 20). The lack of accurate information about cataract services and unmet patient expectations have also been documented (21-24). It may be true

that many donor-supported programmes, which are usually limited to 3-4 years of implementation, may not be 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 community mobilisation campaigns, and communication between different teams are critical and can either increase or significantly decrease demand for and uptake of surgery.

Similar to 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 within the community, geographical accessibility, affordability of services, staff interpersonal skills such as attitudes, competencies and counselling skills (25). Just like for a skilled birth, a quality cataract surgery requires an equipped, well-managed and patient-centred health system. Our findings are also in line with the findings of a systematic review of studies on barriers to cataract surgery in Africa, which reported that a range of individual, community and system levels factors affected the uptake of cataract surgery (20). In line with other research, our findings show 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 fee elimination itself is not an ultimate solution, as the perceived quality of care, community attitudes and other competing priorities remain important deciding factors.

Our research has a number of programme implications:

1. Large scale cataract programmes should be planned and designed through the health system strengthening lens, i.e. identifying strengths and weaknesses of the health system, within which the programme is being designed. One should also consider how the risks arising from the system weaknesses can be minimised and how specific system components can be strengthened to maximise the effectiveness and efficiency of the programme;
2. Specific considerations should be given to adequate numbers of human resources required by such large programmes to prevent staff shortages and burnout; staff should be appropriately trained and regularly supervised;
3. Programmes should also consider strengthening facility level data management systems and find technological solutions for linkages between outreach camp and hospital datasets.
4. Programmes should consider investments in strengthening hospital drug management systems and supply chains to prevent out of stock situations
5. Consideration to other potential bottlenecks should be given at the programme design stage and mitigating factors should be put in place. Particular attention should be given to engagement with CHWs and other community teams, including effective communication between different teams, appropriate planning of camps and surgery schedules to avoid cancellations.
6. Community mobilisation campaigns need to be well planned and communicated on time to have sufficient time for sensitising communities.

7. Information about surgery needs to be comprehensive but culturally appropriate. All staff, who interact with potential patients at the community, camp or facility level, should be trained and have access to a standardised information package about the surgery. Information should be available in local languages and in accessible formats. Information package should include pre-surgery, surgery and post-surgery information. Clear information for patients who cannot be operated on should also be included.
8. Patient counselling should be given adequate time within the treatment protocols and pathways of care. Surgical and outreach teams should clearly identify staff responsible for counselling within their teams. All staff should be appropriately trained with the involvement of former patients.
9. Engagement with patient champions, who can promote positive attitudes to surgery should be systematically supported, including training, support and motivation of such patients.
10. There is a need to put in place better follow up mechanisms post-surgery, especially for the elderly or other patients with limited mobility. Options for follow up at the nearby facilities should be considered.
11. Programmes should identify patients who are at risk of drop out; e.g. very old patients, those who live on their own, have additional disabilities or specific cultural beliefs; and develop targeted strategies to improve their access to services; there is a need for better understanding of such subgroups, what drives their decisions or who may be effective in influencing their decisions.

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/fact-sheets/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. Bozzani F, Griffiths UJLLSoH, Medicine T. Situation analysis of eye health care in Zambia. 2011.
5. Lindfield R, Griffiths U, Bozzani F, Mumba M, Munsanje J. A Rapid Assessment of Avoidable Blindness in Southern Zambia. *PLOS ONE*. 2012;7(6): e38483.
6. WHO. Universal eye health: A global action plan 2014–2019. Geneva: World Health Organization; 2013.
7. 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.
8. Afolabi MO, Daropale VO, Irinoye AI, Adegoke AA. Health-seeking behaviour and student perception of health care services in a university community in Nigeria %J *Health*. 2013; Vol.05No.05:8.
9. Sara M. A review of health seeking behaviour: problems and prospects. *Health Systems Development Programme*. University of Manchester; 2003.
10. Thaddeus S, Maine D. Too far to walk maternal mortality in context. *Social science & medicine* (1982). 1994;38(8):1091-110.
11. 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.
12. 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.
13. 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.
14. 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-.

15. 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.
16. Ayeni E, Bekibele C, Baiyeroju AJNJoO. Service uptake in UCH, Ibadan: a time flow study. 2005;13(2):49-53.
17. Lewis C, Abrams K, Seervai S. Listening to low-income patients: obstacles to the care we need, when we need it. 2017.
18. 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.
19. 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.
20. Sakara A, Namooq MY, Badu-Nyarko SK. Misconceptions and Rumours About Family Planning Among Moslem Males in Tamle Metropolis, Ghana. 2014.
21. 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.
22. 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.
23. 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.
24. 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.
25. 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-.
26. 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.

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