

Cataract Surgery Uptake in Uganda

2018

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ACRONYMS AND ABBREVIATIONS

CATCH	Co-ordinated Approach to Community Health
FGDs	Focus Group Discussions
HCWs	Health Care Workers
HIMS	Health Information Management Systems
IAPB	International Agency for the Prevention of Blindness
IDI	In-depth Interviews
LMIC	Low- and middle-income countries
OA	Ophthalmic clinical officers
OCOs	Ophthalmic clinical officers
ONs	Ophthalmic nurses
REC	Research Ethics Committee
SAGE	Social Action Grant for Elderly Persons
UNCST	Uganda National Council for Science and Technology
VHTs	Village Health Teams
WHO	World Health Organisation

SUMMARY

Background: Cataract remains the leading cause of blindness in low- and middle-income countries. The prevalence of blindness in Uganda is estimated to be about 1% in the general population and 9% in the people aged >50yrs and the highest burden is thought to be in Karamoja and Busoga regions. The leading causes of blindness in the country are cataract and trachoma. This study sought to understand cataract surgery uptake 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 uptake of cataract surgery.

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 for all the patients who had been identified and referred for cataract surgery under the CATCH programme in selected districts of Karamoja and Busoga regions of Uganda between July 2016 to June 2017. Qualitative data was collected in both regions through in-depth interviews and focus group discussions from purposively selected patients – both those who underwent surgery and those who did not, health care workers and community leaders.

Results: Out of the 640 patients who were screened and referred for surgery in the study period, the records of surgery were available for 217 (33.9%) patients. The total number of patients operated in the study districts in the same period was 920 with 217 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. Due to this discrepancy the study could not estimate the actual rate of uptake of surgery in these regions. Qualitative data shows that several Individual, community and programme/health system factors have influenced the uptake of cataract surgery with experiences of previously operated patients being one of the most critical factors. Other factors identified included cultural beliefs and rumours; fear, availability of family support; distance to health facility and removal of the user fees. The study provides some interesting insights into a relationship between programmatic/systemic factors and individual patient perceptions and beliefs. It shows that a well-organised and appropriately managed system with positive attitudes of staff members 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 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

According to the World Health Organization (WHO), 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 per cent 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. The prevalence of blindness in Uganda is estimated to be about 1% in the general population and 9% in the people aged >50yrs, and the highest burden is thought to be in Karamoja and Busoga regions (4). The leading causes of blindness in the country are cataract and trachoma.

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, 5).

Patient health seeking behaviour determines uptake of surgery, while health seeking behaviour itself 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 (6). Therefore, the success of any health intervention depends on both its accessibility and acceptability, both of which relate to broader individual and social factors (7). 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 to service uptake (8). 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 (9). 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).

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 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 (10). 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. This study was designed to better understand patient health seeking behaviour and to complement the evidence base on the uptake of surgery in the contexts where the surgery is available for free at the point of use. It is envisaged that the findings will be particularly useful in the development of patient mobilisation campaigns and the organisation of cataract services, as well as helping to maximise the surgery uptake and efficiency of services.

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. 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 Uganda the programme was implemented in Karamoja and Busoga regions. The camp mobilisation in Karamoja was mainly through the Village Health Teams (VHTs), who could move around the community living in manyattas. In Busoga region a number of mobilisation strategies were used, including VHTs, radio announcements and public address systems. In some instances, when cataract patients were already known, they were given phone calls to notify them of the camp dates. In addition, other methods of community mobilisation were used in both regions, including community public functions and church and school announcements.

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 were either transported to the health facility by a project vehicle or were asked to come to another pre-arranged location to be transported. At the surgical health facility there was also a VHT 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 cross-sectional 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 3rd, 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 purposefully selected individuals (patients, health care workers and community leaders).

The study was conducted in seven out of 17 CATCH programme districts of the two regions, namely Buyende, Kamuli and Jinja in Busoga region; and Napak, Nakapiripirit, Moroto and Kotido in Karamoja region. The rationale for selecting these seven districts was that these districts had conducted significantly more surgical camps than the other districts, and the necessary number of patients' records could be obtained easier.

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 FGDs 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 Research and Ethics Committee of the Vector Control Division of the Ministry of Health of Uganda. Permission to carry out the study was also obtained from the Uganda National Council for Science and Technology (UNCST). Written informed consent was obtained from all study participants.

RESULTS

Quantitative findings

The records obtained from the programme show that in total 640 patients were diagnosed with cataract and referred for cataract surgery through the CATCH programme in the study districts, in the evaluation period. Over 71% of all referred patients were from Karamoja region.

The majority of patients referred for cataract surgery were aged 60+ years (77% in Busoga and 85.1% in Karamoja). In Busoga there were more males (55.2%) referred for surgery than females (44.8%); in Karamoja, the proportions were reverse (54.2% females and 45.8% males).

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

Stratification of the Screened population by Gender and Age group				
	Female		Male	
Age group	N =324	%	N =301	%
30-60	46	(14.2)	34	(11.3)
60+	264	(81.5)	253	(84.1)
<30	14	(4.3)	14	(4.7)

Stratification of the Screened population by Region and Gender				
	Busoga		Karamoja	
Gender	N =183	%	N = 456	%
Female	82	(44.8)	247	(54.2)
Male	101	(55.2)	209	(45.8)

Stratification of the screened population by Region and Age group				
	Busoga		Karamoja	
Age group	N =183	%	N = 443	%
<30	11	(6.0)	17	(3.8)
30-60	31	(16.9)	49	(11.1)
60+	141	(77.0)	377	(85.1)

Records of surgery were available for 217 (33.9%) patients referred through screening at the CATCH camps. However, the hospital surgery registers show that in the evaluation period, a total of 920

patients were operated on for cataract with 217 of them being referred by CATCH. This suggests that either 703 of the operated patients were walk-ins or there was a mismatch of screening and surgery records. Also, 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.

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

Uptake of Surgery among screened		
Surgery uptake	No. screened	Percent
No	423	(66.1)
Yes	217	(33.9)
Total	640	
Uptake of surgery by screening status		
Screened	Surgery uptake	Percent
No (Suspected walk-ins)	703	(76.4)
Yes	217	(23.6)
Total	920	

Based on the linked records, there was no difference in the uptake of services by sex or age but the uptake seemed to be higher in the older age group (60+ years).

Table 3: Uptake of cataract surgery stratified by demographic characteristics of patients (based on 217 records that could be linked between screening and surgery registers)

	Total		uptake of Surgery (based on linked records)			
			Yes		No	
Variable	N	(%)	N	(%)	N	(%)
Sex						
Male	310	(48.5)	96	(31.0)	214	(69.0)
Female	329	(51.5)	121	(36.8)	208	(63.2)
Total	639		217		422	
Region						
Busoga	183	(28.6)	54	(29.5)	129	(70.5)
Karamoja	457	(71.4)	163	(35.7)	294	(64.3)
Total	640		217		423	
Age Group						
<30	28	(4.5)	8	(28.6)	20	(71.4)
30-60	80	(12.8)	18	(22.5)	62	(77.5)
60+	518	(82.7)	191	(36.9)	327	(63.1)
Total	626		217		409	

Qualitative Findings

To collect qualitative data, eight and nine FGDs were conducted in Karamoja and Busoga respectively, while the number of individual IDIs was 37 and 49 respectively.

Table 4: Number of interviews and Group discussions conducted per region

	Karamoja	Busoga	Total
Category of Interview	IDIs		
Female patients operated	5	4	9
Female patients not operated	7	3	10
Male patients operated	2	5	7
Male patients not operated	4	4	8
Community leaders & VHTs	15	14	29
Health Care Workers (OCOs/Ons and Ophthalmologists)	4	19	23
Total In-depth interviews	37	49	86
	FGDs		
Female patients operated	2	2	4
Female patients not operated	0	1	1
Male patients operated	1	1	2
Male patients not operated	1	0	1

Male patients operated and not operated	1	1	2
Male and female patients operated	1	1	2
Female patients operated and not operated	1	2	3
Community leaders & VHTs	1	1	2
Total Focus Group Discussions	8	9	17
Total Interviews (Both FGDs and IDI)	45	58	103

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. 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 three main reasons given by the patients who undertook cataract surgery, explaining why they agreed to the surgery; i) family responsibilities; ii) improvements in livelihoods and iii) 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 livelihoods

A number of patients said that they had accepted cataract surgery because they wanted to get their lost lives back. They did not want to continue being dependent on other family members or friends.

They wanted to move around on their own and not be a burden to their family. Some patients wanted to regain their sight to be able to cultivate their gardens and perform other household chores. Some patients also wanted to move around the community and socialise.

One participant said that she was willing to walk back home because she realised that she could see and was very excited about being independent again.

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 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. VHTs 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 of them even joined the local VHTs to continue educating others about the benefits of cataract 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 being able to see again.

Programme or health system level

Provision of free services

One of the key factors that motivated patients to make a decision to undergo surgery was the provision of free surgery and medicines. Patients said that they were willing to go to hospital because the surgery and the medicines were free. Even when patients finished their first batch of medicines and returned to the facility for 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 surgical health facility and brought back to their communities, which saved them a lot of time. A number of patients also said that if there was no food provided to them at the facility, they would not have turned up for surgery, as they had no money to buy food.

Positive attitudes of healthcare staff

Most patients expressed their happiness about the kindness and care extended to them by health care staff. Many said that they were cared for well while at the facility and some even wanted to stay for a longer period. Many old patients pointed out that the staff showed them respect, which made them happy.

It was also mentioned that the drivers deployed by the programme did a good job; they helped the patients to board the programme vehicle and made them comfortable during their journey. The patients appreciated that the drivers were aware that they were carrying older persons - they did not

drive recklessly and ensured that all patients had their safety belts on. These 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: i) cultural beliefs about eye problems; ii) fear; iii) rumours about cataract surgery; iv) lack of social support; v) distance and transport costs; and vi) 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. For example, in some communities, people believed that blindness was caused by witchcraft; and therefore, those who got blind had to seek care from traditional healers. Some patients interviewed also believed that their pain or vision loss was not caused by cataract but by other reasons. As a result, they continued using herbs to try and address the cause. Some participants, even after accepting and going through the surgery, were convinced that their eye problem was something other than cataract.

Some participants said that the use of traditional medicines for all health issues was very common in their communities, therefore this is what they used when they had problems with eyes.

Some patients believed that their eye problems were inherited; the disease was within their family and hence there was no need to go to hospital. These patients believed that nothing could be done and accepted their blindness as inevitable.

There was also a belief that poor sight was natural for old people and since old people were not engaged in any economic activities, their vision loss did not have any impact on the family and the family had no reason to worry about it.

There were also a number of participants, who linked the seriousness of an eye problem with pain or an inability to see. Therefore, those patients, who did not experience such symptoms, felt no need to see a doctor. This view was particularly common among patients who had trachoma surgery, which removed pain and helped them to see better. These patients did not see any need to go back for cataract surgery, particularly when cataract did not have any major effect on their sight or ability to function. One male patient, for example explained that he declined cataract surgery when it was offered because he could see and was not in pain. Later on, however, when the pain erupted, he regretted his decision. Some patients also believed that going to an eye hospital without pain could be considered as “disturbing the doctors”.

Fear

Fear of cataract surgery was expressed by a number of participants but in different ways. Some feared that their eyes would worsen after the surgery; others had fear of pain and the unknown. Fear was more commonly expressed by patients who had some vision or who were unilaterally blind. These patients feared that the surgery would make them completely blind and prevent them from carrying out their daily chores. One female in Moroto, for example, declined surgery because of the fear that she would lose sight, become immobile and would not be able to perform her day to day activities, such as childcare.

A number of patients were also scared of post-surgery complications and inability to get the necessary medicines, because the team performing the surgery did not conduct post-surgery reviews at home.

Beliefs and rumours about cataract surgery

Negative perceptions and rumours about cataract surgery were prevalent in the studied communities and also prevented some individuals from seeking eye care. The rumour that people get blind after the surgery was reported by a number of participants, including patients, community leaders and healthcare staff.

Some patients believed that the surgery involved removing eyes. Others thought that patients were being used by NGOs to make money.

Those patients who had undergone surgery and had bad experiences or poor outcomes, had a significant impact on the decision of other patients referred for surgery. Both community members and VHTs described how such patients walked around the community telling others how the surgery made their eyes worse. Many study participants said that such adverse cases were always known in the community and played a deterrent role for others.

One factor that contributed to the negative perception of surgery, were unmet patient expectations. A number of patients said that at the time of discharge, they expected to be given food to eat at home, as they were recovering after the surgery. Some patients expected to be paid an allowance to buy food. Some patients wanted to extend their admission period to ensure full recovery and good outcomes. Others wanted health care workers to regularly visit them in their homes to monitor the progress. Several participants pointed out that other health programmes provided them with incentives, such as food or soap. Those who deemed that their expectations had not been met, felt negatively about the surgery and discouraged others from going to hospital.

Lack of social support

A number of patients said that they could not get to hospital because they were blind and old and could not go independently outside their community. One female for example, could not get to the hospital because she could not see the road. Those, who could get support from the family or community were more likely to attend hospital, as one male patient explained:

“It was difficult because my wife had to put me on a motor bike and sit with me, then the taxi people had to direct me to the car and the hospital.”

Patient support was primarily needed to accompany patients to the facility, helping them to get water for bathing, getting them food, making tea, guiding them to the latrine and giving them hot water for cleaning the eye.

There were however different opinions about external support. Some patients felt that there was a need to go to the facility with a helper and those who could not find helpers opted out. Others thought that there was no need to have external helpers, except if one was extremely weak because they were offered good care by the health care workers. On the other hand, those who felt helpers played a key role said that even if the health care workers were supportive, they could not take you to the latrine and move you around.

The reasons given by those who did not have any support were having no relatives to help, and unwillingness of relatives to help due to other competing priorities in the family.

Distance and Transport cost

Distance to the camp and cost of transport were also reported as reasons for not taking up the surgery. This barrier was reported by both patients and VHTs in both regions. Study participants explained that many patients were old and poor and had no means to travel to the hospital, which was far away from their home. Given that the CATCH programme provided transport for most patients, the reason for reporting this barrier in the context of this programme remains unclear. It is possible that patients did not have full information about the programme and believed that they would have to arrange their own transport. Alternatively, in some camps patients had to travel to a pre-specified location from where they were picked up, and it is possible that for some patients even this distance was too long.

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. In some instances, this was due to misinformation that people had received about the surgery. For example, some participants believed that the recovery time after the

surgery could be as long as two months, as this is what they had heard from other patients. These participants worried that they would not be able to carry out their daily economic activities and provide for their family's basic needs.

Some patients said that the timing of surgery offered to them was not suitable due to their farming activities, which required them to be present at the farm.

Programme/system level factors

The main themes identified here were i) waiting time; ii) poor patient counselling; iii) poor communication between health care teams; iv) poor post-surgery follow up; v) lack of adjustments for patients with disabilities; vi) numbers and skills of healthcare staff; vii) attitudes and behaviours of healthcare staff; and viii) integration of screening into other government programmes.

Waiting time

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 organized over a long period of time. This meant that patients referred for surgery had to wait to be transported for surgery. In a number of cases, the camps were cancelled or rescheduled resulting in frustration of those patients who attended. One female patient for example, explained how she heard about the camp, was willing to attend, went a few times but each time the camp was closed.

Some patients had to wait at the facility because there were only a few surgeons who were very busy, leaving patients unattended for a long time. As a result, a number of patients gave up on surgery and left. In some cases, patients would spend up to three days waiting for their surgery and some would give up.

Overall, waiting times were more commonly reported in Karamoja than in Busoga.

Poor counselling

Generally, the health care providers were reported to be polite to the patients. However, a number of participants pointed out that once at the camp, they did not receive sufficient information and had limited opportunities to ask questions or seek clarifications, as health care workers were very busy attending to large numbers of patients. The issue of training on counselling skills was raised by health care workers themselves, with many saying they had not been trained to counsel patients, but they were the ones doing it.

A number of participants raised issues about the format of counselling, content of information provided and language barriers. Some healthcare workers said that they needed a designated counsellor trained to provide information in the right way, because improper counselling resulted in inaccurate or misinterpreted information and impacted negatively on patients' decision to take up the surgery.

Some patients explained that in their cases there was no opportunity to talk to the doctor because the doctors were busy just calling out patients' names and asking them to walk into a room, or just examining them and giving them medicines. Some patients did not want to disrupt busy doctors, and some did not know what to ask.

In some cases, poor information given during mobilization campaigns resulted in patients' misunderstanding and subsequent refusal of the surgery. For example, one female patient described that during the camp, she was not told about the surgery and she expected to go home after the screening. She did not have any arrangements put in place with regards to her work and home duties and had to decline the surgery because she could not go to hospital straight away.

Communication between healthcare teams

Communication between VHTs 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 VHTs to mobilise and sensitise patients. However, some VHTs reported that sometimes the communication was delayed, and the mobilisation of patients was hurried. The villages covered by screening camps were big and the VHTs were strained to reach everyone in the time given. As a result, some patients missed the surgery date or could not attend due to other activities, such as farming.

In certain instances, the camps were postponed or rescheduled to another location, but the VHTs and the patients were not informed. The patients who turned up felt disappointed and did not attend the camp again.

Poor post-operative follow-up

Some patients and even VHTs 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, 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 their home, because many patients could not move on their own and others were held up with family responsibilities. This however happened only in a few cases. In the majority of cases healthcare workers did not visit patients at home.

Lack of adjustments for patients with disabilities

Patients with additional disabilities also thought that the programme and health facility could not address their needs. For example, one patient with mobility difficulties was screened and referred for surgery, but her wheelchair could not fit into the programme vehicle which was full of other patients. As there were no other means to transport her to the facility, her son had to wheel her to the health facility, while the vehicle followed behind them.

Number and skills of health care staff

One of the problems related to poor quality of care was inadequate numbers of healthcare staff, particularly in very busy camps, resulting in long waiting times and cancellations. For example, some patients reported that staff would sometimes send patients back home because they were short-staffed and tired. They would give patients appointments for other future dates, but some patients felt upset and would not return to the camp.

Some participants said that the staffing problem also affected the pre-surgery counselling. Busy and tired staff would have to sacrifice time that would otherwise be spent communicating with and counselling patients, which led to misinformation and fear.

The lack of a resident surgeon in some facilities was also reported to increase waiting times between the referral and the surgery. As such, facilities would wait for a visiting surgeon to come, resulting in the number of patients dropping off in the meantime.

Finally, 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 surgery or could not be operated on. In such cases, patients were mis-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 or because they had another 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 districts the problem of misdiagnosis of patients was due to staff shortages, rather than staff lacking in skill. In Karamoja for example, only OCOs went for village screening. The OCOs were usually in a hurry and did not have time to explain to patients their condition and whether they would qualify for a surgery or not. Some of these patients would come to the facility, but they would be sent back because their cataract was inoperable or because they had a different eye disease. Again, such patients would feel that the surgery was denied to them and they would spread negative rumours about the programme in their community.

Attitudes and behaviour of health care workers

Some patients and VHTs 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 nurses would send away people from the health facility because they were dirty. Sometimes surgeons would postpone or cancel the surgery, either because they wanted to be paid upfront or because there were too many patients waiting and they considered the prospect of performing a high number of surgeries on the same day to be unsafe. Such attitudes discouraged patients from coming back or advising others to go to the camp.

Integration of screening into other government programmes

Both patients and VHTs complained about linking the screening camps with the Social Action Grant for Elderly (SAGE) programme, which happened only in Karamoja. SAGE is a government scheme where older people come to pick up their financial support provided by the government. The disbursement of funds takes place in designated pay points that are near their homes. On some occasions in Karamoja the screening camps were organised at the time, when people came to pick up their grants and people were taken for an eye examination without any prior information on screening. Many people were unhappy about such arrangements; those, who were referred to surgery did not have anyone to escort them to the health facility and did not have any clothes to change into. Some patients said they felt they were ambushed. Many patients transported to the health facility for surgery escaped and went back home feeling angry and frustrated.

Healthcare workers on the other hand said that linking the two programmes worked to their advantage, as a very large number of patients with cataract were identified and referred to hospital on those days. This arrangement also helped to reach out to the most vulnerable people in society, such as people with disabilities, who are often difficult to reach due to their mobility difficulties.

DISCUSSION

Poor uptake of cataract surgery has been reported previously in different settings (3, 11, 12). 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, had been removed.

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

First, we could not establish the actual rate of uptake of cataract surgery in these two regions in Uganda, as only 33.9% 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 on. However, only a third of the records available in the two data sets was aligned. The most likely explanation of this discrepancy are the gaps in documentation, particularly at the hospital level, with patients operated on being 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 (13).

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 by both individual patients' characteristics including their culture, knowledge and beliefs, and programmatic/systemic level factors. An interesting insight from this specific study was a relationship between programmatic/systemic factors and individual patient perceptions and beliefs. 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 to 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 (12,14-18).

Side factors which arise from both individual and community characteristics, including perceptions of severity of the eye problem, 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 (11,14,19). The lack of accurate information about cataract services and unmet patient expectations have also been documented (20-23). 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 community mobilisation campaigns and communication between different teams are critical and can either increase or significantly decrease demand for and uptake of surgery.

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 a number of programme implications as follows:

1. Large scale cataract programmes require significant numbers of staff to avoid exhaustion and staff burnout; staff should be appropriately trained and regularly supervised;
2. Community mobilisation campaigns need to be well-planned and have sufficient 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, have this information to hand and are trained to use it. Culturally appropriate information packages will need to be translated into the local languages and should be made 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 VHTs and other community teams; communication between different teams, appropriate planning of camp and surgery schedules to avoid cancellations.
6. Programmes need to identify patients who are at risk of drop out, such as single women, very old patients, those who live on their own or have additional disabilities 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, as well those patients who have specific cultural or religious beliefs.
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 post-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.

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