

Understanding why patients with cataract refuse free surgery: the influence of rumours in Kenya

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Summary

OBJECTIVES To understand the reasons that hinder people from uptake of sponsored cataract surgery.

METHODS A mixed methods (qualitative and quantitative) approach was used. During routine screening activities at Kwale District, Kenya, local residents with visually impairing cataract were clinically assessed and offered free surgery. Interviews were conducted using a semi-structured guide that covered different aspects related to acceptance of cataract surgery including knowledge of others who underwent surgery and their outcome. Analysis focused on differences between people accepting and people refusing surgery and the reasons for non-acceptance of surgery.

RESULTS Ninety interviews were conducted, 48 with people accepting and 42 with people refusing free surgery. Those who accepted surgery generally reported good outcome in others, while people who refused surgery often reported to know someone who worsened or even become blind after surgery. Many of these 'failed cases' were prominent figures in the local community, and most of them had already died. Glaucoma was the single most common underlying medical condition. On being re-interviewed, several people admitted that they had actually never met someone who had unsuccessful surgery but only heard rumours.

CONCLUSION In Africa, a rumour of blinding eye surgery is not uncommonly being used by patients to justify their refusal to have cataract surgery. Underlying reasons appear to be related to shame, fear of surgery or missing social support. Improved awareness of the general population regarding eye conditions and their management, involvement of the family and local community in decision making, good surgical outcomes and appropriate counselling are possible methods to enhance acceptance.

keywords Africa, barriers, cataract, Kenya, rumours, sponsored eye surgery

Introduction

Reducing the barriers to cataract surgery will be critical if eye care programmes in Africa are to reach their goals of eliminating avoidable blindness by the year 2020 (Lewallen *et al.* 2005). Health system barriers include the availability and accessibility of hospitals providing surgery, quality of surgery and costs of services (Johnson *et al.* 2000).

Community and individual barriers include lack of family support, traditional beliefs, fear and stoicism (Rotchford *et al.* 2002; Geneau *et al.* 2005). Even in the best case scenario (where all fees and transport are covered and where there are good outcomes), some elderly people continue to refuse sight restoring surgery (Briesen *et al.* 2010).

In Africa, quantitative methods rarely help us understand the reasons for refusal of surgery. Many elderly patients are hesitant to mention their real concerns about surgery, giving excuses that will not offend a service provider. Inability to afford fees is often mentioned as the main reason not to undergo surgery (Kessy & Lewallen 2007). Several qualitative studies, however, have revealed that fees were not a main barrier and even if sufficient resources were available, uptake remained low (Courtright *et al.* 1995; Rotchford *et al.* 2002; Chibuga *et al.* 2008). Acceptance of cataract surgery is not explained by a single factor only, and there is a larger body of evidence about the importance of social support (Courtright *et al.* 1995; Nichter 2002; Geneau *et al.* 2005). Rumours of blinding eye surgery are not uncommonly mentioned by patients

S. Briesen *et al.* **Why cataract patients refuse free surgery?**

who refuse surgery but their influence and function for eye care has not yet been explored. We sought to assess in a setting where cataract surgery is provided at no tangible cost to the patient, what factors continued to lead patients to refuse cataract surgery.

Methods

The study took place in Kwale District (population 600 000), located on the south coast of Kenya. The population mostly earns their living from subsistence farming or fishing. The Kwale District Eye Centre (KDEC), a comprehensive eye centre with an established and trusted community base (Lewallen *et al.* 2005), is the major eye care service provider for the District. Patients with cataract are identified through a network of paid and supervised field-workers. At regular intervals, following community-based announcements, a team from KDEC visits pre-selected sites in the district and field-based screening is carried out. Those detected with a visually impairing cataract are routinely offered free surgery, free transport and free food at the hospital. Lack of awareness and access is believed to be minor barriers to cataract surgery for people residing in Kwale District. Annually, around 1000–1200 patients with cataract are identified in Kwale District, among whom 80% agree to have surgery.

A mixed methods (quantitative and qualitative) approach was used to carry out this study. Informed consent was obtained from each participant, and ethical approval was granted by the ethical committee of the Kenyatta National Hospital, Nairobi.

The sample included Kwale inhabitants with operable cataract (defined as visual acuity (VA) of $<6/18$ in the affected eye) who presented at a screening site organised by KDEC during 2008. Patients were examined by an experienced ophthalmic nurse; if found to have an operable cataract, the patient was counselled; the counsellor explained about cataract, cataract surgery, risks and visual prognosis. All patients were offered free surgery (with free transport and food). Patients then fell into two self-selected groups: people who accepted cataract surgery and those who refused surgery.

For the purpose of this study, a sample of cataract patients with equal numbers of patients accepting and refusing surgery were desired. The inclusion criteria were willingness to participate and being visually impaired in at least one eye ($VA < 6/18$) because of cataract. People with different grades of visual impairment were interviewed ranging from visual impairment in one eye and normal sight in the other to people with bilateral blinding cataracts. The World Health Organisation (WHO)

classification of vision was used (normal vision is $6/18$ or better, visual impairment (VI) is $6/24$ to $6/60$, severe visual impairment (SVI) is $5/60$ to $3/60$ and blindness is $<3/60$). Classification is by the presenting vision in the better eye.

As there were few patients who were either severely visually impaired or blind, for analysis, these two groups were combined to one larger group titled SVI/blindness.

A standardised, pre-tested questionnaire was used to collect data from all patients on age, sex, level of education, literacy, marital status and prior cataract surgery in one eye prior to the interview.

Using a separate semi-structured interview guide as a framework, interviews lasting 30–60 min were conducted. All interviews were carried out by the same person (MK), a local person fluent in the common languages. The interviewer was exclusively employed for the purposes of this study and did not participate in the screening or treatment of patients. The interview covered four aspects ('question complexes') related to acceptance of cataract surgery. The first question complex asked about knowledge of others who underwent surgery and about the outcome of their surgery. The second question complex dealt with questions concerning knowledge of cataract and its treatment options. The third question complex referred to perception of free and paid surgery and about the donors. The fourth question complex, asked only among those refusing surgery, covered reasons for unwillingness to have surgery. All interviews were tape recorded, transcribed and translated into English. All transcripts were checked in detail by one of us (SB), and a coding framework was developed. This process was performed on an ongoing basis so that previous transcripts were often revisited. Data analysis was an iterative process, and modifications to the framework were necessary as analysis progressed. The themes that emerged from this analysis, along with illustrative statements made by the participants, are presented.

For quantitative findings, odds ratios (95% CI) and *P*-values were generated to compare findings between those accepting and those refusing surgery.

During analysis, it was noted that many people reported to know someone who had undergone an unsuccessful eye surgery. All of these participants were re-visited at their homes to provide more information about the person who had a poor outcome. Subsequently, we tried to locate this person to find out where the operation took place. If the patient was operated at KDEC, the operation records were used to assess the surgical outcome. If the person was operated elsewhere

S. Briesen *et al.* **Why cataract patients refuse free surgery?**

he or she was visited at home, interviewed and examined.

Results

A total of 90 people were interviewed, 42 who had refused surgery and 48 who had accepted surgery. The mean age was 64, ranging from 45 to 86 years. There were 50 women and 40 men. Most participants were illiterate (88%), with no formal education (91%). There were no significant differences in socio-demographic variables among those who refused and those who accepted surgery (Table 1). Overall, 27% had already undergone cataract surgery in one eye, 17 who accepted and nine who refused surgery. Visual impairment (presenting, best eye) was similar among those who accepted and refused surgery.

Lack of social support

The lack of social support from the family or from the community was the primary reason (54% of respondents) given for refusing surgery – either they said they could not go because they had to seek permission from a family

member or they could not go because someone at home (e.g. sick child) was dependent on them.

‘I cannot go today. I have to ask for permission from my eldest son and he is not at home’.

(Woman, 67 years, rejected surgery).

Only 12% mentioned fear, 7% said their reduced sight was normal for their age, and 19% said they could still fulfil most of their daily duties.

‘I have the fear that I might lose my remaining vision like what happened to my mother and still I have some small children to take care of’

(Woman, 63 years, Mother was operated with end-stage glaucoma).

Free surgery or a fee, and does paying a fee lead to better quality?

The majority of people (90%) mentioned that free surgery is good and they appreciate this service, with some saying that they actively sought out free cataract surgery.

Table 1 Characteristics of people who refused or accepted cataract surgery

Variable		Accepted (<i>n</i> = 48) # (% within Group) or Mean (SD)	Refused (<i>n</i> = 42) # (% within Group) or Mean (SD)	OR (95% CI) or Students <i>t</i> -test (for continuous data)	<i>P</i> -value
Age	Mean	64.35 (11.8)	62.46 (10.55)	0.54	0.592
	Less than 50 years	4 (8.3)	3 (7.1)	Baseline	
	50–60 years	13 (27.1)	15 (35.7)	0.7 (0.1–3.5)	0.612
	61–70 years	22 (45.8)	17 (40.5)	1.0 (0.2–4.9)	0.971
Marital Status	Above 70 years	9 (18.8)	7 (16.7)	1.0 (0.2–5.8)	0.968
	Not married/widowed	20 (41.7)	20 (47.6)	Baseline	
Educational Level	Married	28 (58.3)	22 (52.3)	1.3 (0.6–2.9)	0.571
	None	42 (87.5)	40 (95.2)	Baseline	
Literacy	Primary school or more	6 (12.5)	2 (4.8)	2.9 (0.5–15)	0.198
	Illiterate	40 (83.3)	39 (92.8)	Baseline	
Previous Cat-OP	Literate	8 (16.7)	3 (7.2)	2.9 (0.7–11.6)	0.115
	No	31 (64.6)	33 (78.6)	Baseline	
Gender	Yes	17 (35.4)	9 (21.4)	2.0 (0.8–5.2)	0.144
	Male	22 (45.8)	18 (42.9)	Baseline	
Visual Status (WHO)*	Female	26 (54.2)	24 (57.1)	0.9 (0.4–2.0)	0.777
	Normal (6/18 or better)	19 (39.6)	16 (38.1)	Baseline	
VA of eye scheduled for surgery*	Visual Impairment (6/24–6/60)	19 (39.6)	20 (47.6)	0.8 (0.3–2.0)	0.632
	SVI and Blindness (worse than 6/60)	10 (20.8)	6 (14.3)	1.4 (0.4–4.7)	0.583
VA of eye scheduled for surgery*	6/24–6/60	15 (31.3)	20 (47.6)	Baseline	
	5/60–3/60	8 (16.7)	8 (19.1)	1.3 (0.4–4.4)	0.632
	Worse than 3/60	25 (52)	14 (33.3)	2.4 (0.9–6.1)	0.067

SVI, severe visual impairment; VA, visual acuity.

*ANOVA: Visual Status: *F*: 0.323; *P*-value: 0.630; VA (scheduled for surgery): *F*: 8.65; *P*-value: 0.054.

S. Briesen *et al.* **Why cataract patients refuse free surgery?**

‘...I’ll be very grateful if I get free treatment (surgery). In fact, I was looking for such offers for a long time. I even went up to another village, where there was a screening but the surgery was not sponsored’.

(Man, 67 years, accepted surgery).

The nine people (five women and four men) who stated that free services were not good were not different from the others in terms of socio-economic status, visual impairment or acceptance/refusal. Several people mentioned that the matters of fees are of less importance than the quality of the service, and 25% agreed that payment would result in better services (no difference by acceptance or refusal). People estimated the overall ‘costs’ for the hospital for one cataract surgery at the hospital at around US\$130 (ranging from \$40 to \$350). A ‘fair price’ for them was considered to be at around US\$35 (ranging from \$15 to \$150).

‘Anything given free is not good, it’s better to pay for the costs so that you get good services’

(Man, 66 years, refused surgery).

Very few people could correctly report who sponsored the surgery and 60% mentioned that they had no idea about the sponsors. Among those who offered an idea most (75%) incorrectly reported that it was supported by government.

‘It is the Government which has decided to pay for the costs so as to help the needy. Free surgeries are good and helpful.’

(Woman, 59 years, accepted surgery).

Decisions influenced by others who have had eye surgery

Overall 86% of people, similar for those who accepted and who refused surgery, mentioned to know someone else who had surgery. In most cases, individuals belonged to the extended family or lived in a nearby village. People who accepted surgery were 2.6 times (95% CI 1.1–6.3, $P = 0.18$) more likely to comment positively about the outcome in others compared to those who refused surgery.

‘There is a woman in my village who really benefited. She was totally blind and now she has resumed normal life.’

(Woman, 65 years old, accepted surgery).

Only one person who accepted (2%) but 16 people who refused (38%) reported that they knew someone who worsened or even became blind after surgery. Thus, people who reported poor outcomes in others were 28.9 times (95% CI 3.6–230.7, $P < 0.0001$) more likely to refuse

surgery. Respondents reported that some of those ‘failed cases’ even threatened others not to come to the eye centre.

‘...there is an old man whose eyes got worse after surgery. Actually, he is threatening us about going to the hospital.’

(Man, 68 years, refused surgery).

Rumours that someone might lose remaining vision after surgery were common, being mentioned by around one third of people.

Who are the failed cases?

Of the 17 people who named someone whose vision worsened after surgery 15 could be re-interviewed. Two had moved locations and could not be traced. Several people referred to the same individual; in one case, this was a well-known village elder who was blind from glaucoma. He underwent glaucoma surgery at a very advanced stage and was referred to as a ‘failed case’ by four people. After becoming completely blind, he started blaming the hospital for having spoilt his eyes. In total, only six individuals were referred to by the 15 people who could be re-interviewed. Six individuals admitted, on re-interview, that the information they gave before was not correct: they did not know someone in particular, only having heard rumours that surgery ‘makes you blind’. Some said they feared an operation, and the rumours were simply an excuse not to have surgery.

Among the six real ‘failed cases’, four had already died. Among the remaining two, one had unsuccessful glaucoma surgery and one suffered from an unclear bilateral optic atrophy after but not related to cataract surgery. Records were available for three people who had already died: two had end-stage glaucoma and one had complicated and unsuccessful cataract surgery.

Discussion

While it is intuitive that good surgical results are likely to encourage acceptance of surgery and are an effective means of promoting eye care services, the experience of a poor outcome is more complex. Reports of poor surgical results were often based on rumours rather than actual cases of poor outcome. Rumours could be considered an ‘excuse’ not to undergo surgery because there is no perceived need to do so. However, for the majority of elderly patients with cataract refusing surgery, this explanation appears too simplistic. The fact that all patients in this study self-presented at a local site for

S. Briesen *et al.* **Why cataract patients refuse free surgery?**

screening indicates perceived impairment and willingness to seek medical advice and treatment. So why are rumours so common and what is the relationship between rumours and social support for medical interventions?

Rumours have been defined by social scientists as 'collective sense making in response to uncertainty or threat'. In rural Africa, where illiteracy is high and educational levels, in particular among elderly people, are low, rumours abound. Of course these rumours do not apply only to eye care; in fact, they are more common in other areas, such as sexually transmitted diseases or vaccinations (Nakato 1994; Feldman-Savelsberg *et al.* 2000; Dodoo *et al.* 2007; Schumaker & Bond 2008; Kaler 2009). One of the most common rumours regarding eye surgery is that the doctor will take out someone's eye and replace it with a goat or sheep eye. Other rumours are that eyes are deliberately or unintentionally spoiled by students in training. Rumours often increase if the doctor is not local; for example, when a doctor from the Western region of Kenya started working at our hospital, people refused to undergo surgery, believing that he would intentionally spoil their eyes because they were not of the same tribe.

Accurate medical information about cataract and cataract surgery has been slow to reach rural communities – therefore, the 'space' has been mostly occupied by local knowledge & explanations, often in the form of rumours. But rumours are not just products of miscommunication or lack of information (Schumaker & Bond 2008). Even when 'accurate' information is provided, rumours will continue, because they reinforce popularly held social realities that are difficult to change. Rumours often function to manage a threat or ambiguous situation (DiFonzo & Bordia 2007). Patients with cataract often believe that their eye problem can be solved with drops or glasses. When surgery is recommended and the patient is forced to decide whether or not to undergo an invasive procedure, rumours appear helpful to justify refusal and to gain back control about a situation he or she is not prepared for.

From related research, we know that elderly patients with cataract often consider themselves a burden to their relatives or have feelings of shame (Briesen *et al.* 2010) and it is likely that these feelings act as a barrier having hindered them to address their problem of reduced sight at home. It appears that many patients are in an ambiguous situation whether to tolerate the status quo and not to 'disturb' their relatives with their problem or whether to make an effort and improve their sight through surgery. The lack of communication with family members may contribute to elderly patients rejecting surgery. Perceived

lack of social support, not uncommon among the elderly in Africa, may be caused by unwillingness (or inability as a result of distance) of elderly patients to demand support from relatives, refusal of relatives to provide support or a combination of both.

Our results show that knowing someone who benefited from surgery is a strong predictor for accepting surgery, emphasising the need for practicing high-quality surgery and for providing adequate knowledge about the procedure and expected outcomes. How can eye care providers in Africa ensure that they achieve good outcomes given their limited resources and the low financial contributions from patients? Secondly, how can pervasive negative rumours regarding surgery be reduced and social support for elderly patients enhanced? While it may seem that the best way to reduce rumours in the community is to provide high-quality surgery for every patient, this answer is insufficient.

Our findings suggest that there are three main interventions necessary to have a positive impact on the perceptions of eye surgery in the community. The first is to enhance the knowledge of eye diseases and treatment options among the general population. Second, cataract surgery must be of high quality with good outcome. This requires proper patient selection and use of modern equipment and techniques [biometry guided small incision cataract surgery (SICS) or Phaco] to reduce the likelihood of surgical complications, undetected comorbidities and poor outcome. For those who are not likely to gain visual recovery, whether treated surgically or conservatively, emphasis needs to be placed on appropriate counselling to avoid unrealistic expectations. If doubts remain as to whether a patient understands the nature, severity and visual prognosis of his eye disease, preference should be given to non-invasive treatment instead of surgery. This reduces the risk that an unsatisfied patient will blame the eye doctor or hospital for having spoiled his or her eyes. Finally, social support for the elderly must be enhanced. Patients operated on before 'blindness' (when the individual is still productive and has not yet lost status in the society) can assist social support for surgery (Chibuga *et al.* 2008). While the family remains the final arbitrator in decisions to access surgery, women's groups and religious organisations, among others, may help promote social support of the elderly in rural societies where family support is often limited.

To achieve success in preventing cataract blindness in Africa providing a good-quality surgical outcome is important but insufficient; eye care programmes must shift attention to improving knowledge in the community, transparency of their service and social support by the family and others.

S. Briesen *et al.* **Why cataract patients refuse free surgery?**

Acknowledgements

This project was supported by the University of Nairobi, the Kwale District Eye Care Programme and Seva Canada. We are grateful to Mwanasha Kibiriti for her work in the field and the entire team at KDEC. We also recognise the patience and understanding of patients interviewed for this project.

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