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OPHTHALMOLOGY | RESEARCH ARTICLE

Assessing the fear of cataract surgery in rural Kenya

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Abstract: Purpose: To explore the fear of cataract surgery experienced by the residents of the Kwale district of southern Kenya. **Methods:** The Kwale Eye Centre (KEC) is the only stationary specialist hospital in the Kwale County of southern Kenya. Patients attending the Centre as a walk-in clients during the data collection period were screened and recruited to the study. Fully informed consent was obtained. Qualitative semi-structured interviews (SSI's) were used for data collection. Each interview followed a question guide and was recorded in a digital-audio format. The interviews were transcribed verbatim and thematic analysis performed on the consequent transcripts. **Results:** A total of 20 SSI's were performed. Most preoperative fears are directly linked to or provoked by "rumours" that surround cataract surgery; 65% of participants identified fear originating from narratives passed on to them by friends and family. These rumours ranged from inaccurate reporting of the process of cataract surgery to completely unfounded information. The most common intraoperative fear of cataract surgery was concern over the injection. A frequently noted postoperative fear was that of suffering further eye damage. **Conclusion:** The long-standing service the KEC has provided might have decreased the fear surrounding cataract surgery as a consequence of increased awareness. Yet, even when accurate information is provided, rumours continue to spread. Knowledge of the cataract surgery plays an incredibly important role in

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Mr Thomas Gabbott is currently a fourth year medical student studying at the University of Leeds, UK. He received his Bachelor of Science Hons in International Health from the Nuffield Centre for International Health and Development within the Leeds Institute of Health Sciences. Mr Gabbott has developed a keen interest in ophthalmology throughout his academic career, reflected in his role as President of the Leeds Medical School Ophthalmology Society. He is currently undertaking research analysing the effectiveness of a mobile-app that could succeed the need for face-to-face follow-up appointments subsequent to cataract surgery. Over recent years, Mr Gabbott has also pursued a passion for eye healthcare in an international setting. This lead him to conduct his research in sub-Saharan Africa studying the fear of cataract surgery. Eventually, he hopes to work closely with health services in these countries to improve access to eye healthcare where it has previously lacked.

PUBLIC INTEREST STATEMENT

The World Health Organization launched the VISION 2020 global initiative in 1999 to eliminate avoidable blindness by the year 2020.

Cataract is clouding of the lens in the eye which prevents clear vision. It is avoidable and easily treated with very successful sight-restoring surgery; yet over 20 million people worldwide are blind as a consequence of unoperated cataracts. Hence, there are barriers preventing people from accessing the required eye healthcare.

The Kwale Eye Centre in southern Kenya is the only stationary specialist hospital delivering vital eye care to the 650,000 inhabitants. Previous studies in the area demonstrated that rumours underpinned by fear were a key obstacle locals suffered in accessing cataract surgery. This study hopes to explore their fear in greater detail thus determining how to overcome this barrier—therefore coming one step closer to achieving the VISION 2020 goal.

decreasing fear across all the operative stages. This study shows a great deal of fear is not rational and may perhaps be significantly lessened if addressed.

Subjects: African Studies; Ophthalmology; Ophthalmic Surgery

Keywords: Africa; Kenya; Fear; Barriers; Cataracts

1. Introduction

Multiple barriers surround cataract surgery in every country, but in developing countries (particularly in rural Africa), lack of education, adherence to traditional healthcare approaches, lack of family support and difficulties in reaching eye care facilities make challenges even greater (Geneau, Lewallen, Bronsard, Paul, & Courtright, 2005; Rotchford, Rotchford, Mthethwa, & Johnson, 2002). Stakeholders involved in eye care in developing countries have invested great amounts of money to improve availability and outcome of services; with various results (Binagwaho et al., 2015). Yet fear as a barrier in accessing cataract surgery remains a challenge. This can be broken down as fear of poor surgical outcome, the operation itself and “the unknown” (Athanasiov et al., 2008; Cox, 2002; Dhaliwal & Gupta, 2007). In some individuals, fear of surgery might be so prominent that a sight-restoring operation will be postponed until blindness occurs.

Quantitative data collection rarely aids us in understanding the reasoning behind refusal of cataract surgery. Even when tangible barriers cited as grounds for declining a necessary operation are removed (all fees paid and transport to and from the hospital provided), some patients still decline surgery and are tentative to provide their genuine reason for refusal as not to offend the service provider (Briesen et al., 2010). A qualitative study conducted in the Kwale District of southern Kenya demonstrated that rumours surrounding cataract surgery were greatly influential over patient’s uptake of the service in the area (Briesen et al., 2010). Rumours of blinding eye surgery were commonly noted as justification for refusal of the operation, whilst the genuine underlying reasons were associated with fear and shame.

Eight years on from the Briesen *et al.* study, we sought to explore whether the residents of the Kwale district of southern Kenya still feared cataract surgery and the factors that unpin their anxiety towards the operation. Cataract remains the commonest cause of preventable blindness in developing countries thus fear acting as a barrier in accessing cataract surgery needs to be reduced in order to achieve the *Vision 2020* global target of eliminating avoidable blindness by the year 2020 (Gullapalli, Rohit, & Abhishek, 2011; Lewallen & Courtright, 2000; Lewallen et al., 2005). Few studies have explored fear of cataract surgery in detail thus preventing targeted management strategies (Aboobaker & Courtright, 2016; Gyasi & Amoaku, 2008). We hope that the results of our study will contribute to the understanding of the complex mechanisms of accepting surgery and will help achieving the global goal of overcoming barriers in accessing cataract surgery.

2. Methods

The Kwale Eye Centre (KEC) is the only stationary specialist hospital in the Kwale County of southern Kenya providing eye care to the 650,000 inhabitants. The Centre, formed in 1993, has a long-standing, effective outreach programme dependent on field workers to mobilise the community, screen and educate the remote rural population (Lewallen et al., 2005). The outreach programme’s success can be partly accredited to the nature of patient selection. If patients are in need of surgery, they are provided with transport to the KEC on the day of screening, undergo surgery within 24 h and are provided with transport back within 48-h post-operatively. This system has been vital in reducing the rate of avoidable blindness in the area. Alternatively, patients with sight diminishing cataracts self-present to the hospital’s day clinic to receive an eye check-up (walk-in patients) and are consequently scheduled for surgery in the future. The numbers of walk-

in patients are increasing over the years, most likely as a result of a growing recognition and appreciation of KEC's services.

The main inclusion criteria two-fold: “*underwent cataract surgery at Kwale Eye Centre*” and “*be willing and capable to participate in the interview*”. As a consequence of limited time and resources, only those patients who had prior cataract surgery and were attending the Centre as a walk-in clients during the data collection period were screened and recruited to the study.

Full informed consent was obtained for each individual (ethical approval granted by the ethics board of the KEC and the NCHID ethics sub-committee, University of Leeds, UK) in accordance with the Declaration of Helsinki. A detailed ophthalmic investigation was then performed on each research member. A standardised, pre-tested questionnaire was subsequently used to collect the demographics of all the participants (age, sex, level of education, literacy, marital status), in addition to details regarding their previous cataract surgery.

A qualitative approach was used for data collection. Three pilot semi-structured interviews (SSI's) were conducted and translated to gauge understanding of the questions for both participants and the professional translator and consequently, minor wording alterations were made. Each interview followed a question guide and was performed in a private room within the KEC. The question guide was composed of four main sections. 1. The patient's view towards their cataract prior to surgery and how it affected their quality of life. 2. Knowing they were going to have a cataract operation, the thoughts and feelings the patient experienced before undergoing the procedure. 3. During the cataract surgery, how did the patient feel and why. 4. After the operation had been completed, how did the patient feel and why?

Each SSI was recorded in digital-audio format (with consent) and stored on an encrypted device. No paper notes were taken during the interview and no pecuniary incentives or otherwise were offered to recruit patients. Each interview was transcribed verbatim and thematic analysis performed on the consequent transcripts (iteration was utilised to render the analysis effective). The emerging sub-themes were then amassed into a thematic framework within a spreadsheet to encapsulate the findings.

3. Results

A total of 20 SSI's were performed, lasting between 40 and 60 min each. Eighteen out of the 20 interviews were conducted in the local language of Swahili (or derivatives thereof) with 2 performed in English. The mean age of the participants was 62, ranging from 20 to 95. Fourteen interviewees were male and six were female. Eight had received no formal education in their life, seven had attended primary school and five had attended education to a higher level than that of primary school. Six participants classified themselves as unemployed (never had a formal job), four said they were retired (once had a formal job) and 10 members said they were still working.

Overall, preoperative visual acuity ranged from perception of light to 6/24. The time since undergoing cataract surgery ranged from two weeks prior to the interview to 29 months prior to the interview. Intraoperative complications of the research participants were few—only two members were noted to have any (one patient had very loose zonules that required intraocular lens implantation in the sulcus and one had some cortex material left in the anterior segment after surgery). Postoperative best corrected visual acuity spanned from hand movements (can only visualise someone waving a hand in front of them from a distance of 25 cm away) to 6/6.

3.1. Pre-operative fears

Most preoperative fears are directly linked to or provoked by “rumours” that surround cataract surgery. A rumour is defined as “*a currently circulating story or report of uncertain or doubtful truth*”. Sixty-five percent of participants identified fear originating from narratives passed on to

them by friends and family. These rumours ranged from inaccurate reporting of the process of cataract surgery (thus falsifying the unknown parts) to completely unfounded information.

“People tell me that for the cataract to be removed, the eye has to be removed and replaced with an eye from a goat or a sheep...the eye would be removed and the socket be closed”
(Male, 61 years, retired, above primary school level of education)

“I heard stories from people that the eye will be removed and placed on a table, washed with medicine, then placed back in the eye socket”
(Male, 60 years, currently still working, no formal education)

“I was scared because people told me that the eye will be cut into two pieces”
(Male, 73 years, currently still working, primary school education)

Fifty percent of participants expressed concerns about having to endure surgery only to find that the final visual outcome being no better than their original eyesight. This fear was predominantly felt by those patients who were currently working or had other family members to look after.

“To have the operation and the pain and the stitches and the drops, but no vision after”
(Male, 45 years, currently still working, no formal education)

Furthermore, data revealed that if a patient was to have a poor surgical outcome, this information was disseminated within the local community rapidly creating further negative opinions relating to surgery.

“There are some people who told me stories that there were people who were operated and they lost their vision”
(Male, 60 years, currently still working, no formal education)

3.2. Intraoperative fears

The most common intraoperative fear of cataract surgery was concern over the injection (used to anaesthetise the eye); 40% of participants noted various aspects of the injection that increased their worry during surgery—ranging from location (disliking the eye itself to be injected) to the pain encountered.

“I feared the injection of the eye. I knew that injections could be injected in the arms, buttocks, but not in the eye”
(Female, 60 years, unemployed, no formal education)

Thirty percent of people referred to “cutting” as an aspect of the operation that increased their fear. Whilst some participants used scissors to describe the instrument performing the surgery, others mentioned a knife.

“During the operation, I heard the scissors cutting. This made me have a small fear”
(Male, 70 years, currently still working, no formal education)

Furthermore, it is evident that rumours had an influence over some participants understanding of the injection and the “cutting” of the eye. Spanning the two sub-themes, 15% of patients mentioned aspects of each category that they feared—even though they were factually incorrect.

“I would fear the injection because of those people who were saying that when you are injected, the eye comes out”
(Female, 59 years, unemployed, no formal education)

A further 20% of interviewees stated that one of their greatest concerns was being operated on by inexperienced staff members. This was a consequence of numerous factors, for example, discussion within the operating theatre (requesting surgical instruments) and the youthful appearance of some of the healthcare staff. This led to fear that the operation might then have undue negative consequences.

“I did fear that the surgeon who was supposed to be operating on me was giving instructions to another person... I got scared knowing maybe he was a student”
(Male, 60 years, currently still working, primary school level of education)

Interestingly, the use of an ophthalmic microscope during the operation created mixed feelings of intraoperative fear. For many, it was their first experience of this large machine so had no experience of what it did—thus their fear increased during the operation. For others, they believed that as a consequence of the KEC having such large, expensive machine, it meant that the treatment was of high standard; therefore reducing their fear levels.

“When I saw big machines, I was also scared because they might be placed on the eye. So I was worried as I had not seen them anywhere before”
(Male, 61 years, retired, above primary school level of education)

“I felt that the hospital had big machines. High quality. I had never seen these machines elsewhere, so this helped me to reduce the fear”
(Male, 58 years, currently still working, above primary school level of education)

3.3. Postoperative fears

The most common postoperative fear was that of suffering further eye damage. This was discussed in reference to both the operated and un-operated eye. A total of 35% of participants mentioned this fear (15% worrying about the operated eye and 20% fearing the un-operated eye).

“I do fear that maybe the blind eye will make the operated eye bad again. It will contaminate the operated eye”
(Male, 60 years, currently still working, no formal education)

Concomitant with further eye damage, the fear of postoperative instructions was cited by 20% of participants. Whilst each contributor mentioned a different aspect of fear relating to their instructions (from quantity to adherence), the underlying premise was the lack of understanding about them led to vision loss concerns amongst the patients.

“There were so many instructions and medicines. I was worried that if I did not follow them correctly, I might lose the vision again”
(Male, 66 years, currently still working, primary school level of education)

Perhaps the most surprising finding was the postoperative fear relating to the restriction of sexual intercourse—as stated by 10% of participants. Each male interviewee (with primary school level education or higher) expressed feeling concerned that they could not have sexual intercourse for at least two weeks following surgery. They were fearful that their wives would leave them for another male partner.

“The instruction of not to have sex for two weeks, that one, many people feared...I thought maybe my wife could be taken by other men because of the waiting of the two weeks”
(Male, 60 years, currently still working, primary school level of education)

4. Discussion

Literature details that even when affordable, high-quality eye healthcare services are available, people needing surgery in sub-Saharan Africa do not present to hospitals for a variety of reasons (Eloff &

Foster, 2000). The long-standing service the KEC has provided (through both the stationery Centre and outreach programme) might have enabled less fear surrounding cataract surgery since the time of the Briesen *et al.* study as a consequence of increased awareness and education. Concurrently, other parts of Africa (with less developed eye healthcare) might suffer from populations that are more fearful about cataract surgery as a consequence of lack of knowledge. But why is fear of the operation still a key hurdle to overcome in those accessing cataract surgery in an area of exceptional outreach? What needs to be done to reduce this barrier and consequently achieve the *Vision 2020* aim?

Fear is defined as “*an unpleasant emotion caused by the threat of danger, pain or harm*”. It is not surprising then that rumours formed the largest aspect of preoperative fears—findings that are consistent with those of Briesen *et al.* eight years on. The high illiteracy rate in combination with low education levels of the area create an environment where word-of-mouth transmission provides the largest source of information to the local population. Thus, if accurate medical knowledge of cataract surgery has failed to reach rural communities, local explanations fill in the “gaps” within the information and consequently, rumours are formed. These rumours are often fraught with inaccurate details of pain and trauma to the eye, so the “unpleasant emotion” causing fear increases and the barrier to accessing cataract surgery is maintained.

Yet, even when accurate information is provided, rumours still continue to spread (Briesen *et al.*, 2010). They are established to uphold social norms that are difficult and arduous to change. A large portion of Kwale county who suffer from cataracts often believe that they will regain their vision solely through the use of eye drops or glasses. If offered surgery, the patient has to decide on a sight-restoring, yet invasive and unknown-to-them, procedure in comparison to the social norm of fearing (and subsequently declining) surgery. It is then understandable that they use the rumours surrounding cataract surgery as a means to justify fearing the operation.

Rumours give people a sense of belonging. Spreading rumours can often result in personal recognition and popularity—thus giving both psychological and social advantages (Davidhizar & Dowd, 1996). Knapp identified four types of rumours (Knapp, 1944). One of these included “*fear or bogey rumours*” that are designed to instil fear or anxiety in others—yet are actually expressing unconscious or repressed emotions of the one spreading the rumours. The concept of “rumour spreading” is carried out in all cultures, by all types of people, throughout the entire world (Ribeiro & Blakeley, 1995). Thus, fear acting as a barrier in accessing cataract surgery as a consequence of rumours in the rural county of Kwale in southern Kenya could be attributed to the personal benefits gained from spreading false information that are not only present in sub-Saharan Africa, but across the globe.

Another significant fear is the intraoperative anxiety encompassing the equipment used during the operation. In Swahili, there is not a direct translation of the word “*operation*”. The word “*kusafishwa*” (English translation: “*wash out*”) is often used when referring to cataract surgery in Kenya. The closest translation of the word “*operation*” in Swahili is “*upasuaji*” (English translation: “*wrench open*”). The latter is more aggressive and harsher. It installs fear into patients if used in the context of cataract surgery. However, the use of “*kusafishwa*” implies to patients that the operation just uses water to wash out the eye. They become fearful when they learn about the use of needles, injections and scissors. This fear is somewhat inevitable as a consequence of lack of Swahili vocabulary to accurately describe cataract surgery.

It has been previously noted that in order to achieve success in preventing cataract blindness across Africa, a good quality surgical outcome is important (Briesen *et al.*, 2010). Whilst these current findings support that notion (poor surgical outcome increases fear levels thus maintaining a barrier in accessing cataract surgery), it is not the only factor that causes fear to act as a barrier. The more knowledgeable a patient is about the operation, the less they fear it (Chaudry *et al.*, 2014; Nijkamp *et al.*, 2004, 2002). Knowledge of the cataract surgery plays a very important role that spans all the operative stages. When exposed to greater details about the operation, fear factors such as rumours, the use of students, further eye damage (to the other eye) and the

restriction of sexual activity all become obsolete. Patients who are more aware of the process of cataract surgery consequently have a greater understanding of what is likely to happen to them throughout the surgical process.

5. Limitations

We exclusively interviewed patients who had already undergone cataract surgery. We do not know how our study population differs from those patients with blinding cataract, who decided not to attend a screening or finally denied surgery. However, we believe that the type of “fears” might be somehow similar among these two groups; only that family support or behavioural strategies to overcome fear might be better evolved in those accepting surgery than in those refusing. A second limitation is the comparatively small sample size in our study. This however could, at least partly, be compensated by having used a qualitative approach with a very detailed interview procedure.

6. Recommendations

This research supports the notion of giving more information to gain greater understanding of the procedure surrounding cataract surgery. The use of previous patients and the personal link with the outreach programme’s field-worker (who has seen many patients successfully undergo the process) is key to increasing confidence within the local population. Of note is the importance of professional behaviour and empathy of the patients’ awareness whilst waiting for the operation, in the operating theatre and throughout the recovery process.

7. Conclusion

Fear is a normal consequence of the decision to undergo most surgery. Some fear rational especially in a situation where a part of the body central to the senses is so involved and conducted under a local anaesthetic. Cooperation of the patient is key to a successful outcome, and it seems that the main way to gain this is by communication and addressing the patient’s fears. As this study shows a great deal of fear is not rational and may perhaps be significantly lessened if addressed. More studies are needed on this interesting and important issue to breaking down the barriers to those accepting cataract surgery albeit in Africa or in the more developed world.

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Competing Interests

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