



Research Report

Barriers to Women's Access to Cataract Surgery in Mwinilunga District, North Western Province, Zambia



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Executive Summary

The purpose of the study was to explore the barriers women face in accessing surgery in Mwinilunga District, North Western Province, Zambia. The study was commissioned in response to data showing a consistent pattern of lower rates of surgery uptake by women, as compared to men, in the first 2 years of 'The Saving Sight, Changing Lives' project implemented by Orbis in partnership with the Ministry of Health in the North Western Province, Zambia funded by Seeing is Believing.

The study consisted of in-depth qualitative interviews with 17 women who were diagnosed with cataracts and referred to the district hospital, and who did not take up surgery by the time of the study.

The findings of the study highlighted two main mechanisms which delayed and/or prevented women from accessing surgical treatment.

First, women interviewed reported a number of delays in their journey to accessing health services, of between 9 months up to 14 years. The delays included first trying home remedies and traditional medicine; religious convictions of healing; choosing to wait for an eye specialist to visit their area during outreach after diagnosis and referral; advice obtained to wait for the cataracts to mature; receiving poor counselling at diagnosis on what cataracts are and details on the treatment, as well as fears of surgery and negative stories of cataract surgery within communities, made worse by the general limited education levels of the women.

Second, after accessing services and receiving a referral for surgery at the district hospital, a number of cultural and socio economic barriers were encountered preventing women from accessing surgery. These included, limited decision making autonomy of women; the high costs associated with travel to district hospitals and limited financial resources within households. These findings highlight the intersection of low decision making autonomy by women and the high costs associated with travel to district hospitals in the context of constrained household financial resources, as one of the main mechanisms influencing women's uptake of cataract surgery.

A key limitation of the study is no comparative information on the barriers experienced by men, to allow for a deeper understanding of the gender-specific dynamics at play.

Key recommendations were proposed based on the findings of the study:

It is important to bring families into counselling sessions (or where counselling is unavailable, information sessions) when women are referred for surgery to discuss the potential benefits of sight-restoring surgery, explore transport options and address misconceptions. It is also important to identify the main decision maker within the particular family, dependant on the marital status, as the person making the ultimate decision around surgery for the woman could be the husband/partner, children or siblings.

The project should develop and implement more comprehensive plans to create awareness that surgery is free and transport can be arranged for patients to travel to

the district hospital. General awareness on the benefits of sight restoring surgery should be raised within communities as well. The use of patients as 'patient mentors', who have already undergone surgery successfully should be explored. One example could be the involvement of a woman who has successfully regained her sight through surgery in the roll-out of Orbis's facilitated film screenings.

The quality of counselling and/or patient education/information provided when patients are initially diagnosed as well as referred should be further explored to establish whether the findings in this study are prevalent throughout the districts and to identify best practices in counselling patients which could lead to an increase in uptake of surgery by women.

The project should continue to monitor the uptake of surgery among women and consider conducting further research to compare the experiences of men and women, to provide more in-depth understandings of the key findings highlighted in this study.

Background

Blindness is an increasing global public health problem. Thirty-nine million people were estimated blind in 2010. Approximately two thirds are women and 87% live in developing countries.¹ Over half of all blindness is due to cataracts, although cataracts can be routinely treated with surgery. In addition, women are more likely to be affected by cataracts than men because they have a higher life expectancy increasing their likelihood of being affected by age-related diseases such as cataract and have a slightly higher incidence of cataracts than men. Women are 10-15% more likely to have cataracts than men in developing countries and in Africa, women account for between 53% and 72% of all people living with cataracts.

Given the higher prevalence and incidence of cataracts among women, they should account for between 60-65% of all cataract surgeries. However, studies in developing countries have consistently shown female patients accessing cataract surgery at lower rates than men. The results of a literature review of cataract surveys conducted in developing countries found the cataract surgical coverage rate was 1.2–1.7 times higher for men than for women. Ensuring women receive cataract surgery at the same rate as men is essential to make significant strides in decreasing the prevalence of cataract blindness. The prevalence of cataract blindness could be reduced by up to 12% if women received cataract surgeries at the same rates as men.²

In general, reasons for the unequal access to cataract surgery by women in developing countries can be attributed to gender defined social roles and socio-economic factors. These include limited education and decision making power in households, as well as limited access to financial resources as well as restrictions on travel.

While general patterns has been discovered in the available literature, it is important for projects aimed at reducing avoidable and treatable blindness to understand the specific barriers at play in the project location, especially for female patients.

Purpose of the study

The purpose of this study is to explore the local barriers women experience that prevents women's equitable access to eye care services in a project site in the North Western Province of Zambia.

The Saving Sight, Changing Lives project implemented by Orbis in partnership with the Ministry of Health, aims at reducing avoidable blindness by establishing, strengthening and improving access to high quality eye health services at primary, district and secondary hospital levels in the North Western Province of Zambia, with a focus on cataract services and trachoma. The project monitoring data has shown a

¹ Pascolini D, Mariotti SPM. *Global estimates of visual impairment: 2010*. British Journal Ophthalmology Online 2011; 10

² Abou-Gareeb I, Lewallen S, Bassett K, Courtright P. *Gender and blindness: a meta-analysis of population-based prevalence surveys*. Ophthalmic Epidemiology 2001;8:39-56

consistent pattern of under representation of women receiving cataract surgery. Of the 922 cataract surgeries conducted by the end of 2014 throughout the province, 57% were on men and 43% on women. This is despite cataract being free within the public health system.

The specific objectives of the study are:

- 1) To improve the project understanding of the barriers to eye health services among female cataract patients by exploring the socio-cultural, economic factors that prevents women's equitable access into eye care services;
- 2) To develop recommendations to inform the project strategy to increase women's uptake of services in a sustainable manner.

Method

The study explored the barriers female cataract patients face in Mwinilunga District in Zambia using qualitative in-depth interviews. Interviews were conducted with women diagnosed with cataracts and referred for surgery, who did not access surgery by the time of the study.

Mwinilunga District was selected out of the eight districts in the province because the district had the highest disparity between men and women accessing surgery based on project data. A sample of female patients was randomly selected. While the study is qualitative and the findings are not generalisable, random sampling was used to increase the credibility of sampling. A list of all women booked for surgery at Mwinilunga District Hospital, who did not have surgery during the periods January 2015 and November 2015 was drawn up. Random systematic sampling was employed to select a total of 17 women for interviews. The youngest was aged 20 and the oldest 83 years, five were between the ages of 20 and 50 years and 12 above 50 years.

They were contacted and invited to take part in the study. The purpose of the study was explained and they were given the opportunity to provide consent for participation. An open ended interview schedule was developed and the interviews took place from 25th November 2015 through to 1st December 2015. The women were interviewed at their homes in their home language Lunda. After the interviews, an ophthalmic clinical officer discussed surgery options with the women and their families, answered clinical and surgical related questions they had and the women were offered the opportunity be booked for surgery at a time convenient for them with transport arranged by the hospital. The interviews were taped recorded, transcribed and translated into English for analysis. Qualitative data analysis was conducted using QDA Miner 4 Lite qualitative data analysis software.

Study participants were limited to female cataract patients who did not access services. Comparisons between male and female patients not accessing surgery and/or a comparison between female patients who did and did not access surgery was therefore not possible.

Results and Discussion

Findings highlighted two main mechanisms which delayed and/or prevented women from accessing surgical treatment.

First, women reported delays in their journey to accessing health services centring on the following:

- Use of home remedies, traditional and religious beliefs
- Seeking a second opinion
- Waiting for cataracts to mature
- Limited counselling provided
- Fears of the outcome of surgery

Second, after accessing services and receiving a referral for surgery at the district hospital, a number of cultural and socio economic barriers were encountered preventing women from accessing surgery. These included:

- Limited decision making autonomy of women
- High costs associated with travel to district hospitals
- Limited financial resources within households

Delays at numerous points in the journey to accessing health services

The women interviewed had visual problems for periods ranging from 9 months to 14 years, 59% had cataracts for between 1 and 2 years, 18% between 2 and 3 years and a quarter (24%) for more than 6 years. All the women interviewed reported a number of delays in the process of accessing health services before being diagnosed and referred for surgery. The delays included first trying home remedies and traditional medicine, religious convictions of healing; choosing to wait for an eye specialist to visit their area during outreach after diagnosis and referral; obtaining advice to wait for the cataracts to mature; receiving poor counselling at diagnosis on what cataracts are and details on the treatment, as well as fears of surgery and negative stories of cataract surgery within communities, made worse by the general limited education levels of the women.

Use of home remedies, traditional medicine, religious beliefs

Seven (41%) reported exploring alternative home practices or seeking the advice of traditional healers when they first started experiencing difficulties seeing, before visiting the local clinic. Furthermore, these women only accessed services at the local clinics after the condition had started to impact their daily lives and the home remedies and other practices had no impact.

“[I waited before going to the clinic] because of the medicine and herbs I used, which made me feel better.”

Three respondents said they waited before going to the local clinic because they believed they would be healed by God, and one reported waiting to see if the condition would resolve itself on its own.

“I believed with God’s power I will be healed freely.”

Seeking second opinion

Six women, after being diagnosed with cataracts at their local clinic and referred to the district hospital, instead of completing the referral, opted to wait to be seen by a visiting eye specialist during outreach at the local clinic, because they did not have the money to travel to the district hospital. This points to a lack of understanding of where cataract surgery can be performed and potential problems with the quality of counselling received when referred, as the eye specialist would refer the women to the district level and women would still have to travel to the district hospital for surgery.

Waiting for cataracts to mature

Furthermore, when these women consulted the eye specialist during outreach, they were told to come back after a period of time as the cataract was not mature.

“When I went to the hospital, I was examined in the eyes with a light and they said the problem was still in the early stage and I was examined with letters from the beginning up to the end, asking me where the letters were facing. However, the doctor said I have to wait at least for six (6) months.”

There is evidence that the practice or protocol of requesting patients to come back at a later stage, increases the delay in accessing services. For example, one respondent who had had cataracts for three years related three visits to the local health centre, one each year to meet with the eye specialist visiting on outreach:

“One year the doctor didn’t come, and [the nurse] she came she gave me medicine and in the second year the doctor came he looked in my eyes and said I must go and come back again. And when he went he took long where they went to a different area to see patients. When he came in October that is when he gave me this [referral] that I should go to Mwinulunga District Hospital.”

This practice of having waiting time for the cataract to mature first before referring women, has been found in other studies to deter women from accessing treatment and was commonly found in settings where no counselling was provided.³

Limited counselling

Another key finding was that most women did not relate stories of being fully counselled about their condition, with many saying they had ‘scars in their eyes’. In the quote below the respondent was able to explain what happened during the consultation in detail and says the doctor only told her to come back with no explanation regarding the condition or diagnosis. There was limited counselling provided to women on why their vision was deteriorating, what cataracts are and how they can be treated.

Interviewer: Could you tell me what happened when you first went to see the doctor/nurse concerning your eye problem?

³ Vaidyanathan K, Limburg H, Foster A, Pandey RM. Changing trends in barriers to cataract surgery in India. Bull WHO. 1999;77:104–10

Respondent: When I told him, he took me at the door and started asking me the number of fingers which he continued changing the numbers to test me to see if am seeing or not. He asked me first I said they are two again I said they are three and final ones were five I said. He got the medicine and gave me. He told me that if the problem continues come in December so that I take you to the district hospital, and that is why am here.

Interviewer: What did the doctor tell you?

Respondent: Nothing, it's only the letters mention, eventually he said that am seeing he just got the medicine and gave me."

The quality of counselling could be an important factor in the delays women face in accessing services, given the limited education levels of the respondents. 50% of the respondents have never been to school while 33% went as far as grade seven (completion of primary school). A further 11% managed to reach as far as grade 9. Only one woman interviewed had managed to complete grade 12 (completion of secondary school). In addition, all spoke the local language, Lunda, which not all health professionals are fluent in. Studies have shown that women, with little or no formal education and low literacy rates are less likely to access treatment and be able to navigate health systems. In fact, female literacy remains the strongest independent predictor of health service utilization by women. Coupled with language barriers or unfamiliarity with the health system the importance of providing detailed counselling to women at diagnosis is evident.⁴

Further is is important that counselling covers the reason as to why patients are sometimes told to come back at a later stage , as many times it has to do with the technique fo surgery that warrants that the cataract is at a certain stage before it ccan be removed.

Fears of the outcome of surgery/ hearing negative stories of cataract surgery

Almost half of respondents (eight) reported the pervasiveness of myths and misconceptions about post-cataract surgery and expressed fears of surgery, which influenced their decision not to have surgery and could have played a part in the delays in accessing services.

"Some people don't get healed when they go through the operation but instead go totally blind."

"Others could say they remove the whole eye clean it and put it back."

Similar findings have been reported in a number of other settings; in a study in Kenya, for example, which found patients who refused cataract surgery, often reported either knowing or hearing rumours of people who have worsened or become blind after surgery.⁵

⁴ Oxaal Z, Cook S. (1998) Health and poverty: a gender analysis. BRIDGE report no 46. Brighton: Institute of Development Studies

⁵ Briesen S, Geneau R, Roberts H, Opiyo J, Courtright P. Understanding why patients with cataract refuse free surgery: The influence of rumours in Kenya. *Trop Med Int Health*. 2010;15:534–9

Socio economic and cultural barriers

Another mechanism resulting in barriers to women's uptake of cataract surgery centred on socio economic and cultural barriers limiting women's decision making ability around health care.

Limited decision making autonomy of women

One of the barriers which is clearly linked to gender norms, was the limited decision-making autonomy of the women in the study and limited control over financial resources.

88% of those interviewed reported having a discussion about the need for surgery with family members after diagnosis of cataracts and referral, with married women discussing the options with their husbands and divorced or widowed women speaking with siblings or their children. The discussion focused on the diagnosis as well as whether the woman should have surgery. In only two cases the woman was the primary decision maker regarding her own surgery. This points to the importance of intra-familial decision making, as most women do not make decisions to access surgery independently.

"It's my children; me I don't make decision on my own"

High costs associated with travel to district hospitals

In over half of the cases (53%), the family were supportive of going ahead with surgery after having a family discussion. However, when taking into account the financial and opportunity costs associated with travelling to the district hospital, which was 150km from most participants' homes, the family decision was that the limited resources available could not be used to pay for the travel costs. None of the women interviewed had income of their own, which in turn limited their autonomy in making the decision to go for surgery or not. It should be noted that most of the women and their families were aware that the surgery is available at no cost, with 29% of reported not knowing the surgery was free.

"My relatives said they don't have money to enable me go to Hospital."

"They [siblings] said we don't have money to enable us to go to Mukinge"

"It's lack of money [for transport] which delayed me."

Many women spoke of their family members not being in the position to provide money for their travel. The costs associated with travel included the transport costs, as well as having someone to accompany them to the hospital, during their stay there and back.

Limited financial resources within households

The households participating in the study were severely financially constrained. On average, respondents reporting living with six other people in the household, with the majority (76%) of households with only one member bringing in an income, 85%

were subsistence farmers and 23% reported no income at all, relying on extended family and religious communities for support.

“Inside my heart I was worried and unhappy [not having surgery], and I thought if I had children they would have organized some money [for transport] and I would have gone to hospital.”

Due to the financial constraints within the household, women could not afford travelling to the district hospital for surgery. Studies conducted in developing countries has shown that “poor rural women often have less disposable income, or control of finances, than men” together with geographical location of services, the costs and transport all impact on their ability to access treatment.^{6 7 8 9}

These findings highlights the intersection of low decision making autonomy by women and the high costs associated with travel to district hospitals in the context of constrained household financial resources, as one of the main mechanisms influencing women’s uptake of cataract surgery. A number of studies have similarly shown that the costs associated with surgery and transport are carried by various family members who mobilise resources to support the patient to access surgery. This process of decision making at the family level is complex and prolonged, with patients often having to wait or negotiate support among their family members ‘for weeks, months, or even years.’¹⁰ More frequently, families are willing to mobilise resources for male relatives rather than female relatives, due to the higher social status of men.

Recommendations

The following recommendations are based on the key findings of the study:

It is important to bring families into counselling sessions (or where counselling is unavailable, information sessions) when women are referred for surgery to discuss the potential benefits of sight-restoring surgery, explore transport options and address misconceptions. It is also important to identify the main decision maker within the particular family, dependant on the marital status, as the person making the ultimate decision around surgery for the woman could be the husband/partner, children or siblings. Orbis will explore how to improve this area of patient support going forward in the project, in conjunction with the project partners.

⁶ Lewallen, S. and Courtright, P. “Gender and use of cataract surgical services in developing countries.” Bulletin of the World Health Organization.80.4 (2002): 300-303.

⁷ Brilliant GE, Brilliant LB. Using social epidemiology to understand who stays blind and who gets operated for cataract in a rural setting. Social Science and Medicine 1985;21:553-8.

⁸ Janine A. Clayton & Alison F. Davis (2015) Sex/Gender Disparities and Women’s Eye Health, Current Eye Research, 40:2, 102-109.

⁹ Kessy JP, Lewallen S. Poverty as a barrier to accessing cataract surgery: A study from Tanzania. Br J Ophthalmol. 2007;91:1114–6.

¹⁰ Geneau R, Lewallen S, Bronsard A, Paul I, Courtright P. The social and family dynamics behind the uptake of cataract surgery: Findings from Kilimanjaro region, Tanzania. Br J Ophthalmol. 2005;89:1399–402

The project should develop and implement more comprehensive plans to create awareness that surgery is free and transport can be arranged for patients to travel to the district hospital. General awareness on the benefits of sight restoring surgery should be raised within communities as well. The use of patients as 'patient mentors', who have already undergone surgery successfully should be explored. One example could be the involvement of a woman who has successfully regained her sight through surgery in the roll-out of Orbis's facilitated film screenings..

The project should provide information in various formats, given that many women are not literate and have limited education, for example, use of appropriate simple language and picture aids where available. Orbis's utilisation of radio is already a step in the right direction in this regard, so tailoring messaging and programmes to address awareness issues is recommended.

The quality of counselling and/or patient education/information provided when patients are initially diagnosed as well as referred should be further explored to establish whether the findings in this study are prevalent throughout the districts and to identify best practices in counselling patients which could lead to an increase in uptake of surgery by women.

The project should continue to monitor the uptake of surgery among women and consider conducting further research to compare the experiences of men and women, to provide more in-depth understanding of the key findings highlighted in this study.

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