Why are children with cataracts brought late for surgery? Qualitative Findings from Tanzania
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Background

Globally there are at least 190,000 children blind due to cataract. Cataracts are likely to be the leading cause of blindness in children in eastern Africa and elsewhere in the developing world. The causes of congenital or developmental cataract in children are not fully understood and there are few practical approaches that can be adopted to prevent cataracts from occurring in the eastern African context. As a result, surgical intervention (cataract surgery) is the treatment of choice for children who are born with or whom develop cataract.

In most developing countries the number of children with cataract being brought to hospital for surgery has been less than the burden of disease in the community. In Tanzania, there are between 1000-1500 children born each year with congenital cataract and probably an equal number of children (<15 years) who develop cataract (after normal vision from birth). In 2004-5, the two surgical facilities in the country undertook 738 surgeries in children, or only about 15-20% of the total anticipated. Reasons for the poor uptake of cataract surgery in children in Tanzania have been well researched. This information cannot be extrapolated to the whole country and there has been limited research on the reasons for poor uptake of surgery among children. We also recognize that many children remain unreached and delays in presentation are still too long. A study based on a sample of 178 children with cataract (74 congenital cataract and 104 developmental cataract) revealed that the mean delay between recognition by the caregiver and presentation to hospital was 34 months, almost 3 years with long distance to the hospital, developmental cataract (versus congenital) and low socio-educational status of the mother predicting excessive delay.

Children blinded by cataract should be operated as soon as possible. Delay in presentation results in less than optimal visual outcome after surgery.

Methods

This research was conducted among children and their caretakers presenting to the Kilimanjaro Christian Medical Complex (KCMC) Hospital in Moshi, Tanzania.

Study population: All children under 16 years of age presenting at KCMC Hospital from September 2002 to November 2004 with congenital or developmental cataract were considered as potential cases.

Data Collection & Analysis: We conducted 117 semi-structured interviews between 2002 and 2005 with parents and guardians of children who came to KCMC for cataract surgery. The interviews were usually conducted on the day after admission and lasted between 40-60 minutes. Overall, 117 parents or guardians accounting for 121 children (55 girls, 66 boys) participated in the study. The interviews were all transcribed integrally and translated from Kiswahili to English. Data analysis was guided by the key principles of the grounded theory approach. With our data set, this approach translated into identifying and coding all references to barriers to care, treatment delays and beliefs related to cataract and cataract surgery. The original transcripts and codes were periodically revisited to look for deviant cases that might help enhance the understanding of therapeutic literatures. Coding of qualitative data was done using the qualitative analysis computer package QSR NUDIST.

Preliminary Findings

Barriers at the family and community levels
This section regroups three themes. The first theme relates to the respondents’ knowledge of cataract and its causes. The second theme explores the impact of beliefs associated with cataract and cataract surgery on the decision-making process. The third theme addresses the issue of gender relations and how it may affect the ability of mothers to pursue health seeking behaviours for their child.

Only five of the 117 interviewees were able to identify the child’s ocular problem as cataract when they first noticed it. Cataract being associated with old age, the majority of informants expressed surprise at the diagnosis, as they were not aware a child could have it. A commonly reported belief is that children’s eyes (especially in the cases of premature babies) are not “fully developed” and that “this white thing” should then disappear on its own when the child grows up and the eyes become “mature”.

In terms of gender issues, the main theme relates to the fact that mothers are often the first parent willing to take action but that their level of influence in the decision making process concerning health care is often low. Many mothers (particularly young mothers) that we interviewed feel powerless to seek medical services outside of the community, even though, in most cases, the mother was the first person to notice that something was wrong with the child’s vision.

Socio-organizational barriers within the health care system
The analysis of the therapeutic literatures revealed that many of the respondents needed to overcome several barriers associated with the health care system before the final admission for their child’s cataract surgery.

Several respondents reported being sent back home by a rural primary care provider with drops or vitamins or nothing at all, and without getting a diagnosis (or were given an incorrect diagnosis). Rural health staff often view the problem as not requiring further examination. This delayed presentation to the surgical facilities by years in a few cases.

Several respondents faced barriers that prevented them from bringing their child quickly to KCMC. Financial considerations remain an important factor, even though there is a program in place to cover surgical fees and some indirect costs (transport, stay at the hospital). There remain indirect costs (leaving work, etc.) that are compounded by the occasional long distance to the nearest health facility. Bringing a child to a dispensary or a local hospital (particularly in the case of single mothers having other children or families with no relatives living nearby) was challenging, particularly in terms of identifying someone to look after the other children while being away. Hospital settings are also perceived by many community members as “dangerous” and “unfriendly” places (fear of being scolded by doctors).

CONCLUSIONS

In this study, we have found that surgical delay in children with cataract results from the presence of various barriers that can be situated at different (interrelated) levels. Different actions can be taken to overcome these barriers. Improving knowledge of primary health care staff is required; in particular they need to recognize a “white spot in the middle of the eye” and know to immediately refer the child to a qualified eye care professional. In addition, counselling efforts (of both parents, when possible) are necessary to enable children to access services in a timely fashion. Finally, coordination of available services (from recognition to referral to surgery) needs to be strengthened.

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