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Review

Melese Kitu[1,2], Kebadnew Mihretie[2] and Taye Abuhay[2]

[1]Eyu-Ethiopia, Kebele 14, Dagmawi Menelik Sub-city, Bahirdar, Ethiopia (Correspondence to Melese Kitu: melesekitu0@gmail.com). [2]College of Medicine

Abstract

Background: Repeated infection with Chlamydia trachomatis causes trachomatous trichiasis (TT). Surgery is the main and preferred method of treatment. However, many people decline surgery despite the availability of free services in nearby health facilities.

Aimz: To identify the determinants of surgery refusal among TT patients in Ethiopia.

Methods: This community-based, case–control study was conducted among 338 cases and 338 controls from 5 October to 17 December 2018. Using systematic random sampling, we selected people who had been operated on (controls) and those who refused surgery (cases) from registration documents and used a pre-tested, interviewer-administered, structured questionnaire for data collection. We used SPSS version 23 to analyse the data and used multivariate logistic regression to identify the determinants.

Results: Having witnessed a poor surgical outcome [adjusted odds ratio (aOR): 3.51, 95% CI: 1.94–6.35] and lack of knowledge about TT (aOR: 1.77, 95% CI: 1.18–2.65) increased the refusal rate for surgery. Having trust in the surgeon (aOR: 0.26, 95% CI: 0.15–0.45), knowledge about eyelid surgery (aOR: 0.32, 95% CI: 0.16–0.64), long duration of trichiasis (aOR: 0.50, 95% CI: 0.31–0.79), decision-making via discussion with the family (aOR: 0.29, 95% CI: 0.13–0.64), frequent epilation (aOR: 0.31, 95% CI: 0.17–0.60), and receiving personal advice (aOR: 0.11, 95% CI: 0.04–0.28) reduced refusal rates.

Conclusion: Refusing to have TT surgery was significantly related to knowledge about upper eyelid surgery, past surgical outcomes, decision-making capacity, and personal influences. Improved systems for upper eyelid surgery should be established in Ethiopia to better manage, and reduce unfavourable, surgical outcomes, and reduce surgery refusal.

Keywords: trachomatous trichiasis, upper eyelid surgery, surgery refusal, trachoma, eye health, Ethiopia

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Introduction

Trachoma, a highly contagious infection caused by the bacteria Chlamydia trachomatis, is the most common cause of eye infections and the eighth most common cause of blindness worldwide (1,2). Repeated infection over many years produces scarring of the inner part of the upper eyelid, which turns the lashes inwards so that they scratch the cornea. When the eyelashes rub on the eye, the condition is called trachomatous trichiasis (TT). Scarring of the cornea impairs vision and causes blindness. Blindness due to trachoma is irreversible once it has occurred, but it can be prevented (3,4).

Trachoma is a public health problem in 42 countries. In 2022, around 125 million people were at risk of blindness due to trachoma and about 1.9 million were either irreversibly blind or visually

impaired. Trachoma causes about 1.4% of all blindness worldwide (5). The estimated total global burden for TT in June 2022 was 1.7 million (6).

Surgery to correct TT is the main and preferred method in all trachoma blindness control programmes in endemic countries, however some patients – those without entropion (inward turning of the eyelid) and having just a few eyelashes in the periphery – can be managed with epilation (pulling out the eyelashes) (7–9).

Countries will be considered to have eliminated trachoma as a public health problem when they have achieved the goal for TT at district level: 15 years who had been diagnosed with TT and who had been given the chance to be operated on by health workers for corrective upper eyelid surgery but had refused. Controls were individuals aged > 15 years Who had been diagnosed with TT and who had been operated on for corrective upper eyelid surgery.

The Ethiopia Central Statistical Agency population projection data for 2017 shows the total population of Mecha District was 372 000. The woreda has 6 urban and 40 rural kebeles (20). According to the district (local) TT patient records, 843 TT patients (controls) who had been operated on were registered in the “service beneficiary registration logbook”, and 1032 TT patients who had the chance to be operated on but refused (cases) were registered in the “TT refusal registration logbook”.

The participants were selected by systematic random sampling from the 2017 registration logbooks. First, numbers were assigned to every individual in the logbook, and then, using a random number generator, a subset of individuals (participants) was selected for interview. Individuals who were not able to communicate were excluded from the study (e.g. those having a psychiatric illness).

Data collection and tools

A pre-tested, interviewer-administered, structured questionnaire was adapted from previous studies and used to collect data (4,11,13–15). The questionnaire was prepared in English and translated to Amharic (local language). Data were collected by 5 nurses and 2 integrated eye care workers (supervisors) who were trained for 3 days by the principal investigator on the study instruments and data collection procedures prior to data collection.

Data management and analysis

The data were entered, cleaned and coded using EpiInfo, version 7. Data were then exported to SPSS, version 23, for further analysis. All required variable recoding and transformation was completed before the final data analysis. Descriptive statistics were computed to describe the collected data. For the categorical variables, frequency and percentages were computed and presented in a table. For the continuous variables, mean and standard deviation (SD) were calculated. Cases and controls were compared via univariate logistic regression and independent t-test. Predictor variables having P-value

Results

Sociodemographic characteristics

This study was conducted from 5 October to 20 November 2018. A total of 338 corrective upper eyelid surgery refusals (cases) and 338 operated controls were included. Females constituted 197 (58.3%) of the cases and 195 (57.7%) of the controls. The majority of respondents [273 (80.8%)] among the cases and 274 (81.1%) among the controls resided in rural areas. Cases and controls differed significantly in age: mean for cases was 48.9 (SD 16.2) years and for controls 52.2 (SD 15.5) years (P = 0.007). There was no significant difference in regard to sex (P = 0.876), marital status (P = 0.891), education status (P = 0.275) or occupation (P = 0.934) (Table 1).

Participants' condition

Compared with controls, more of the cases had trichiasis in only one eye (OR = 1.68, 95% CI: 1.23–2.40). Mean duration of TT was 5.1 (SD 5.4) years for controls and 3.8 (SD 3.7) years for cases (OR = 0.40, 95% CI: 0.28–0.60). Severe pain due to TT was reported by 79 (23.4%) cases and 109 (32.2%) controls (OR = 0.66, 95% CI: 0.55–0.79). More than half the controls [187 (55.3%)] had practised epilation before surgery, whereas only 130 (38.5%) cases had done so (OR = 2.03, 95% CI: 1.49–2.75). The majority of the controls [313 (92.6%)] said they had trust in the health professionals compared with just under half [165 (48.8%)]of the cases (OR = 5.11, 95% CI: 3.19–8.18).

Cases had less knowledge about TT (197, 58.3%) than controls (256, 75.7%) (OR = 2.23, 95% CI: 1.61–3.11). Cases and controls did not differ in access to transport (OR = 0.76, 95% CI: 0.53–1.20). Only 16 (4.7%) cases and 19 (5.6%) controls could not move on their own (i.e. needed assistance). Many more controls (243, 72%) had witnessed a good outcome (success) from surgery than refusals (cases) (141, 41.7%) (OR = 0.55, 95% CI: 0.45–0.68). The majority of the case respondents (325, 96.2%) and controls (307, 90.8%) stated that they made decisions about their health and health-related conditions themselves (OR = 0.40, 95% CI: 0.20–0.77). Almost half (161, 47.6%) of the cases and three-quarters (242, 71.6%) of the controls had taken advice from other persons in addition to health workers in regard to undergoing surgery (OR = 0.81, 95% CI: 0.74–0.88).

Determinants of corrective upper eyelid surgery refusal

Variables associated with eyelid surgery refusal in the univariate logistic regression, at P Table 2).

Multivariate binary logistic regression analysis showed that those who were more frequent epilators were less likely to refuse surgery (aOR = 0.31, 95% CI: 0.17–0.60). Surgery refusal was 71% lower among patients who decided their health and health related conditions in discussion with family members than those who decided for themselves (aOR = 0.29, 95% CI: 0.13–0.64). Those who had lived with TT for a long time (> 5 years) were 50% less likely to refuse surgery than those who had had it for ≤ 5 years (aOR = 0.50, 95% CI: 0.31–0.79). Respondents who received personal advice from other sources as well as from health workers were 74% less likely to refuse surgery (aOR = 0.26, 95% CI: 0.14–0.50). Having witnessed poor outcomes of surgery led to a 3.51 times greater likelihood of refusing eyelid surgery (aOR = 3.51, 95% CI: 1.94–6.35). Respondents who had knowledge about eyelid surgery were 68% less likely to refuse (aOR: 0.32, 95% CI: 0.16–0.64). Those who were not knowledgeable about TT were 77% more likely to refuse eyelid surgery than those who were (aOR = 1.77, 95% CI: 1.18–2.65). Refusal to have surgery was 74% lower among respondents who said they had trust in the integrated eye care workers (aOR = 0.26, 95% CI: 0.15–0.45) (Table 2).

Discussion

Refusal to have eyelid surgery decreased with duration of illness. This contradicts the findings of a study conducted in south Wollo, Mehalsayint District, in which the respondents who had had TT for more than 5 years were 2.56 times more likely not to attend surgery than those in whom the duration of the condition was ≤ 5 years (21). Our findings support those of a study conducted in southern Tigray, Ethiopia, in which participants who had had trichiasis for > 2 years were 60.2% less likely to refuse surgery than participants who had had the condition for ≤ 2 years (18). In a cohort study in Tanzania on 200 TT patients, surgical coverage at baseline was 16.9%, but one year later the surgical uptake was 44.8% (an increase of 27.9%) (22). Over time, patients may be requested to attend many surgery programmes, which may increase the probability of making the decision to have the operation. This finding is supported by a study conducted in northern Ethiopia (23). This may be because the early symptoms were mild, however, over time, due to the progressive scarring effect of the bacteria on the eyelid (24), the inturned lashes that scratch the cornea increased in number (minor progresses to major TT) (25), causing severe pain. As the pain increases, patients may be forced to accept corrective eyelid surgery treatment to relieve the pain.

Practising more frequent epilation was associated with fewer refusals to have surgery. This is supported by the findings of a study in South Wollo, Mehalsayint, which showed that non-epilators had a 3.22 times greater likelihood of not having surgery than those who had had

at least one instance of epilation (21). Even though epilation has an effect comparable to that of surgery for patients with minor TT (

We found that refusal to have surgery was lower among individuals who were knowledgeable about the procedure. This is supported by a comparable study from Tanzania which showed that 26% of those accepting to have surgery suggested that better education and advice about the surgery would help improve services (28). Another qualitative study from Tanzania found that community health workers and patients gave long recovery times, fear of surgery pain and poor anecdotal experiences with surgery as reasons for refusing (29). This was also reinforced by a study conducted in Basoliben, in which the majority of non-operated respondents (81%) had no knowledge about eyelid surgery (30). Patients who had knowledge about eyelid surgery knew that surgery was conducted with lidocaine (without pain) (4), takes a short time to complete and requires only a few days to heal and to return to work. This knowledge may help TT patients to decide on accepting surgery.

In our study, there was greater refusal to have surgery among individuals who had no knowledge about TT. This is supported by a study conducted in Tanzania in which 95.7% of surgery acceptors and 87.7% of non-acceptors had knowledge of the progression of TT to blindness (8% less in the non-acceptors) (28). A study on the natural history of TT showed that it is a high risk for blinding corneal opacity (31). Fear of losing vision comes from knowledge about the potential of TT to lead to blindness, and could have been a stronger motivator among patients who had been operated on to agree to have the surgery; those who refused the surgery may have lacked this knowledge.

Refusal to have surgery was lower among those respondents who had trust in the integrated eye care workers. A study in South Wollo showed non-significant results, but a descriptive statistic indicated that 89.6% of respondents among the non-operated and 98.8% among those who had been operated on (9.2% more in controls) had trust in TT surgeons (21). From interviews with 94 surgeons who were still in the programme in West Amhara, 15% said patients “want an expatriate surgeon (i.e. did not show trust)” as reasons for not presenting for surgery (32). Patients going to the clinic need to have a successful outcome (looking good after surgery), but in clinical trials in the Amhara Region, the surgical failure (recurrence) rate varied from 7% to 50%; eye contour abnormalities varied from 19% to 28%; and granuloma varied from 3.2% to 5.6% among surgeons (33,34). Surgeons who have fewer unfavourable outcomes may earn the trust of patients while those who have many unfavourable outcomes may not. Fear of poor outcomes may be one reason for refusing surgery among patients who did not trust TT surgeons.

Refusals were fewer among patients whose deciders for health and health-related conditions were family members than those who decided by themselves. Decision-making was the difficult

part for many patients in accepting to have surgery (13). Over time, a family member may help convince non-acceptors to have surgery, and hesitant patients may also be more willing to trust family members.

Getting advice from sources other than (or in addition to) health workers reduced the rate of refusing to have surgery. This is supported by a study conducted in Tanzania which showed that, when another person was involved, 22.3% of respondents among acceptors and 19.2% among non-acceptors (3.2% more in acceptors) agreed to have the surgery (28). This may be because individuals who had positive experience of surgery persuaded their friends to accept surgery. In addition, patients could be more willing to trust their leaders. Perhaps this was the reason most patients who had the surgery could be convinced by their kebele leaders and the Health Development Army.

Our study showed that respondents who had witnessed poor outcomes of surgery were more likely to refuse eyelid surgery. This is supported by a study in Tanzania in which patients in a focus group discussion gave, as a reason for refusing surgery, wanting to see how others in the village fared after surgery, and when they saw the rapid recovery of their neighbours, they wanted the surgery for themselves (29). A study in West Amhara showed that, among 94 surgeons who were still in the programme, 9.5% thought that poor surgical quality was one reason for patients not to present to the clinics (32). Patients who had a positive experience of surgery were the best ambassadors to their communities in terms of persuading others to accept surgery. Successful surgery patients would be strong voices in helping to convince the non-acceptors. In contrast, if people see poor outcomes in persons who had the operation or hear horrible stories about surgery, they may refuse to undergo surgery.

This study had some limitations. We included TT cases who had been identified by health workers before the data collection. Since the information was collected from controls who had been operated on, the TT severity grading was not measured. There may also have been a certain level of recall bias.

Conclusion

In conclusion, refusing TT surgery services was significantly related to knowledge, quality of the procedure, decision-making capacity and personal influences. Therefore, offering health education and increasing community awareness about trachoma and its treatment should be encouraged. Poor outcomes are negative provokers of surgery. A strong system should be designed to reduce unfavourable outcomes of eyelid surgery and to identify and manage poor surgical outcomes.

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Competing interests: None declared.

Étude cas-témoins des déterminants des refus de chirurgie réparatrice de la paupière supérieure chez les patients atteints de trichiasis trachomateux en Éthiopie

Résumé

Contexte : L'infection répétée à Chlamydia trachomatis provoque un trichiasis trachomateux. La chirurgie est la méthode de traitement principale et privilégiée. Cependant, de nombreuses personnes refusent les interventions chirurgicales malgré la disponibilité de services gratuits dans les établissements de santé situés à proximité.

Objectif : Identifier les déterminants du refus d'intervention chirurgicale chez les patients atteints de trichiasis trachomateux en Éthiopie.

Méthodes : La présente étude cas-témoins réalisée au niveau communautaire a été menée auprès de 338 cas et 338 témoins entre le 5 octobre et le 17 décembre 2018. À l'aide d'un échantillonnage aléatoire systématique et à partir des documents d'inscription, nous avons sélectionné des personnes qui avaient subi une intervention chirurgicale (témoins) et des personnes qui avaient refusé l'intervention (cas). Nous avons utilisé un questionnaire structuré, administré par un enquêteur et préalablement testé pour la collecte des données. Nous avons utilisé le logiciel SPSS version 23 pour analyser les données et avons recouru à la régression logistique multivariée pour identifier les déterminants.

Résultats : Le fait d'avoir été témoin d'un mauvais résultat chirurgical [odds ratio ajusté (ORa) : 3,51 ; IC à 95 % :

1,94-6,35] et le manque de connaissances sur le trichiasis trachomateux (ORa : 1,77 ; IC à 95 % : 1,18-2,65) sont des facteurs qui ont contribué à l'augmentation du taux de refus de la chirurgie. Le fait d'avoir confiance en son chirurgien (ORa : 0,26 ; IC à 95 % : 0,15-0,45), de posséder des connaissances sur la chirurgie de la paupière (ORa : 0,32 ; IC à 95 % : 0,16-0,64), d'être atteint de trichiasis depuis longtemps (ORa : 0,50 ; IC à 95 % : 0,31-0,79), de baser sa décision sur la discussion avec la famille (ORa : 0,29 ; IC à 95 % : 0,13-0,64), de s'épiler fréquemment (ORa : 0,31 ; IC à 95 % : 0,17-0,60), et de recevoir des conseils personnels (ORa : 0,11 ; IC à 95 % : 0,04-0,28) étaient des facteurs qui ont contribué à diminuer les taux de refus.

Conclusion : Le refus d'avoir recours à la chirurgie du trichiasis trachomateux était étroitement lié aux connaissances sur la chirurgie de la paupière supérieure, aux issues chirurgicales antérieures, à la capacité de prise de décision et aux influences personnelles. Des systèmes améliorés de chirurgie de la paupière supérieure devraient être mis en place en Éthiopie pour mieux prendre en charge, diminuer le nombre des issues chirurgicales défavorables et réduire le refus du recours à la chirurgie.

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