

ORIGINAL ARTICLE

# Patients' Perceptions of Trichiasis Surgery: Results from the Partnership for Rapid Elimination of Trachoma (PRET) Surgery Clinical Trial

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## ABSTRACT

**Purpose:** While quality of life surveys have been conducted in trichomatous trichiasis (TT) surgery populations, little is known about patients' perceptions of the surgical experience and outcomes.

**Methods:** We interviewed a subset of Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial participants 24 months after surgery. Questions focused on current ocular symptoms, perceived daily functioning, physical appearance, and overall perception of surgery. We stratified participants based on surgical outcomes: normal upper eyelid, postoperative TT, or eyelid contour abnormality (ECA) in one or both eyelids. We compared responses between sexes and surgical outcome groups using contingency tables and Fisher's exact tests.

**Results:** A total of 483 individuals participated and 86% were very satisfied with surgery results; 96% reported ocular symptom improvement. Participants with moderate to severe ECA or postoperative TT were more likely to report current ocular problems than those with normal eyelids (46% and 58% vs 34%, respectively;  $p=0.01$  for each comparison). The most common symptom among participants with moderate to severe postoperative TT was feeling lashes touching (blurred vision was the most common among participants with moderate to severe ECA). Overall, 83% stated surgery improved daily life; participants with ECA were less likely to report improvement than others ( $p=0.002$ ). Participants who had moderate or severe postoperative TT were least likely to state that they would undergo repeat surgery (80%), followed by participants with ECA (86%).

**Conclusions:** Postoperative TT and ECA both reduced satisfaction with surgery, but appeared to influence different aspects of life. Improving surgical outcomes both by reducing recurrence rates and limiting ECAs are essential.

**Keywords:** Eyelid contour abnormality, patient satisfaction, surgery, trachoma, trichiasis

## INTRODUCTION

Trichomatous trichiasis (TT) is the leading infectious cause of blindness worldwide. Repeated or chronic ocular infection with *Chlamydia trachomatis* during childhood leads to progressive tarsal conjunctival

scarring, which can lead to entropion (inward deviation of the eyelid margin) and trichiasis (misdirected lashes touching the eye). "Active trachoma", characterized by follicles and/or intense trichomatous inflammation of the upper tarsal conjunctiva, is observed more often in children, while TT is more

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common among older adults. TT requires timely surgical intervention and if left uncorrected, trauma from TT leads to vision loss and blindness from corneal opacification. Trachoma is concentrated in rural, economically-challenged areas where access to clean water is limited and hygienic practices are poor. Worldwide, an estimated 1.3 million people are blind from TT, and currently over 8 million people afflicted with TT are at risk of becoming blind.<sup>1</sup> The World Health Organization (WHO) has employed the SAFE (surgery, antibiotics, facial cleanliness, environmental change) strategy to target trachoma, with the ultimate goal of elimination by 2020.<sup>2</sup> The surgical arm of the strategy calls for timely intervention to prevent vision loss and blindness. While several surgical procedures are available, the WHO recommends the bilamellar tarsal rotation procedure for the correction of TT when new surgical programs are implemented.<sup>3</sup>

Several studies have focused on improving surgical outcomes across different surgical settings, with TT recurrence being the most widely researched. Eyelid contour abnormalities (ECAs), sometimes referred to as “eyelid notching”, also can occur after marginal rotation.<sup>4–10</sup> These ECAs can range from slight cosmetic defects to substantial eyelid notching and lagophthalmos. Researchers have recently begun to explore the ramifications of this adverse surgical outcome.

Two previous studies reported that a significant reduction in quality of life was found in females with untreated TT, even in the absence of vision loss.<sup>11,12</sup> In addition, a study investigating physical functioning measures before and after TT surgery reported significant improvement in physical function after surgery.<sup>13</sup> That study, however, did not investigate how different surgical outcomes may affect participants’ perceptions. The goal of the current study was to investigate the impact of TT surgery on participants by exploring associations between surgical outcomes and participant perceptions of surgery 24 months after the intervention.

## MATERIALS AND METHODS

### Study Population

The Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial is a randomized clinical trial evaluating trichiasis surgery performed with the standard bilamellar tarsal rotation procedure versus the TT clamp.<sup>9</sup> The study was conducted in the Mtwara region of Tanzania, which lies in the south-eastern-most corner of Tanzania. As part of the PRET trial, surgery was offered to all individuals living within the region. The surgical team traveled from village to village in a systematic way, following a screening team who identified all individuals in the

area who needed surgery. Anyone in need of trichiasis surgery was offered treatment. Participants received trichiasis surgery at a local health center or health post, under standard local surgical settings. Specifically, surgery was provided in the village where the participant lived, or in a neighboring village. As with nearly all trichiasis surgery programs in Tanzania, surgery was provided free of charge. Local, experienced trichiasis surgeons, who resided in the region at the time of the study, performed the surgery. With the exception of the project manager, all of the local team members were native to the region and spoke both Kiswahili and the local language, Kimakonde, fluently.

PRET participants living in the Mtwara Rural district in southern Tanzania were invited to participate in a survey focused on evaluating patient perceptions of TT surgery and outcomes during their 24-month follow-up visit in 2011.

### Data Collection

A questionnaire specific to this study was developed and pilot tested (Figure 1). The questions were designed to assess ocular symptoms, perceived daily functioning, physical appearance, and overall perception of surgery. Questions were presented as yes/no questions, with further querying of affirmative responses to determine the degree of problem or the level of satisfaction/dissatisfaction.

The structure of the questionnaire and the number and wording of response options was modeled after that of our previous quality of life questionnaire in trichiasis patients conducted in Ethiopia.<sup>13</sup> The questionnaire was piloted by administering the questionnaire to five participants individually. The principal investigator, project manager and interviewer met after each pilot interview to discuss responses and to determine whether any questions should be reworded. Additionally, after the interview, these five participants were asked individually whether any questions were not clear and whether any additional information would be useful to add. No changes to the questionnaire were made based on the pilot testing. The team deemed that the questionnaire was clear and concise while eliciting the necessary information. A trained interviewer conducted the interview in the local language. All interviews were conducted one-on-one with the participant and interviewer, in a private area where others could not overhear the conversation. The interviewer was local to the region, but was not known by the participants. Additionally, the interviewer was not previously involved in patient interactions in the PRET trial. Interviews were conducted at the site where surgery had been performed 2 years previously.



## Post-Surgical Trichiasis Patients Questionnaire

CID: \_\_\_\_\_

Patient Name: \_\_\_\_\_

You are here today for a follow up evaluation from surgery to correct your eyelashes that were turning under and causing you problems. We would like to ask you a few questions that will help us to understand better the impact your eye surgery has had on you. Are you ready to begin?

1. How satisfied are you with the results of the eye surgery to repair your eye problem?  
 1  Not satisfied  
 2  Somewhat satisfied  
 3  Very satisfied

2. Did your eye surgery improve some of the eye problems that you were experiencing?  
 0  No  
 1  Yes → 2a. How much improvement do you have?  
 1  Some improvement (Still have one or more problems)  
 2  A lot of improvement (Problems are gone)

3. Are you currently experiencing any eye problems?  
 0  No  
 1  Yes → 3a. If YES, please describe: (check all that apply and write in others).  
 Can't see/blurry  
 Tearing  
 Sensitive to bright light  
 Can't close my eyelids completely  
 Feels lashes touching  
 Pain → How much?  
 1  Some  
 2  A lot  
 Has the pain been reduced since you had surgery?  
 0  No  
 1  Yes, somewhat  
 2  Yes, a lot  
 Other: specify: \_\_\_\_\_

4. Did the surgery change how well you can see?  
 0  No  
 1  Yes → 4a. If YES, how much?  
 1  A lot of improvement  
 2  Some improvement  
 3  Somewhat worse  
 4  A lot worse

5. Do you feel the eye surgery has changed your appearance?  
 0  No  
 1  Yes → 5a. If YES, how has it changed it?  
 1  A lot better  
 2  Somewhat better  
 3  Somewhat worse  
 4  A lot worse

6. Has anyone in your household noticed a change in your appearance since having eye surgery?  
 0  No  
 1  Yes → 6a. How would they describe the change?  
 1  A lot better  
 2  Somewhat better  
 3  Somewhat worse  
 4  A lot worse

7. Did your eye surgery change your daily life?  
 0  No  
 1  Yes → 7a. If YES, how has it changed it?  
 1  A lot better  
 2  Somewhat better  
 3  Somewhat worse  
 4  A lot worse

8. If your eye problem came back do you think you would want to have another eye surgery?  
 0  No    1  Yes    2  Not sure

9. Do you have any complaints about the eye surgery?  
 0  No  
 1  Yes → 9a. If YES, what are they? (Check all that apply)  
 Pain during surgery  
 Pain after surgery  
 Time away from family  
 Recovery  
 My eye problem came back  
 I don't like the way my eyelids look now  
 Other: specify: \_\_\_\_\_

10. Did anything make it difficult for you to have surgery?  
 0  No  
 1  Yes → 10a. If YES, what were they? (Check all that apply)  
 Taking care of children  
 Cooking for family  
 Farming  
 Getting to surgery  
 Fear of surgery  
 Other: specify: \_\_\_\_\_

11. Would you recommend to others with inturned lashes to have eye surgery?  
 0  No → If NO, why not? \_\_\_\_\_  
 1  Yes  
 2  Not sure \_\_\_\_\_

FIGURE 1. Patient questionnaire for Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial, Mtwara region, Tanzania.

The 24-month outcome data from PRET were used for this analysis. Specific data collection methods for PRET have been described elsewhere.<sup>9</sup> TT was defined as at least one lash touching the globe, and severity was classified as mild, moderate, or severe based on the number of lashes touching and evidence of epilation.<sup>9</sup> ECAs were characterized as none, mild, moderate, or severe using a grading system developed and validated for this study.<sup>8</sup> A trained examiner assessed visual acuity at 4m monocularly (adjusted to 2m or 1m as needed) under ambient light using the tumbling E version of the Early Treatment Diabetic Retinopathy Study (ETDRS) chart.<sup>14</sup> At follow-up, participants were considered to have improved visual acuity if at least one eye improved by one or more lines.

We grouped participants based on their 24-month ocular status as follows: no upper eyelid problems, mild TT with or without mild ECA in one or both eyes, moderate or severe TT in one or both eyes, mild ECA in one or both eyes, moderate to severe ECA in one or both eyes, or both TT and moderate to severe ECA in at least one eye. Both eyes were included, regardless of whether the eye had surgery within the trial.

### Ethical Clearance and Consent

Written consent was obtained prior to surgery. The project followed the tenets of the Declaration of Helsinki and was approved by the Johns Hopkins and Wake Forest University Schools of Medicine, and the Tanzanian National Institute for Medical Research.

### Analysis

Descriptive measures were evaluated by calculating medians and ranges for continuous variables and proportions for categorical variables. We then compared responses between sexes and surgical outcome groups using contingency tables and Fisher's exact tests using 2-sided *p* values. A *p* value <0.05 was considered to be statistically significant. Analyses were generated using SAS software version 9.2 (SAS Institute Inc, Cary, NC, USA).

## RESULTS

In the Mtwara Rural district, 523 participants completed the 24-month visit. Of these, 518 were invited to participate in the final questionnaire, and all agreed. Of these, 35 participants had undergone repeat surgery and were excluded from further analyses. Prior to surgery, the majority of participants had bilateral severe TT, and nearly a quarter were

TABLE 1. Participant characteristics at baseline and 24 months in the Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial, Mtwara region, Tanzania.

Characteristic	N = 483
<b>Baseline</b>	
Median age, years (range)	55 (18–79)
Female, %	73.7
Better eye visual acuity, % <sup>a</sup>	
20/40 or better	55.8
<20/40–20/60	11.1
<20/60–>20/200	23.3
20/200 or worse	9.8
Bilateral trichiasis, %	85.9
Preoperative trichiasis severity, %	
Mild in one or both eyes	9.7
Moderate or severe in one eye	8.9
Mild in one eye and moderate or severe in one eye	17.6
Moderate or severe in both eyes	63.8
Corneal opacity, % <sup>a</sup>	
None or minor in both eyes	77.6
Covers cornea in at least one eye	22.4
<b>24-month follow-up</b>	
Better eye visual acuity, % <sup>a</sup>	
20/40 or better	43.8
<20/40–20/60	25.0
<20/60–>20/200	24.3
20/200 or worse	6.9
Improvement in better eye visual acuity by 1+ line, %	27.7
Visual acuity improved by 1+ line in at least one operated eye	44.3
Postoperative trichiasis severity, %	
No recurrence	49.9
Mild in one or both eyes	29.0
Moderate or severe in one eye	8.3
Mild in one eye and moderate or severe in one eye	6.6
Moderate or severe in both eyes	6.2
Eyelid contour abnormality, %	
No eyelid contour abnormality	62.7
Mild in one or both eyes	16.8
Moderate or severe in one eye	9.9
Mild in one eye and moderate or severe in one eye	7.3
Moderate or severe in both eyes	3.3
Presence of lower lid trichiasis in one or both eyes, %	20.5

<sup>a</sup>% based on non-missing data; missing baseline visual acuity for three participants, baseline corneal opacity for one participant and 24-month visual acuity for six participants.

legally blind in at least one eye. 47 individuals had both TT and ECA at follow-up, and seven individuals had incident TT at 24 months in an eye without TT at baseline (Table 1). In order to assess the individual effects of TT and ECA, these participants (*n* = 54) were excluded from the remaining analyses.

### Overall Satisfaction

Nearly 87% of participants reported substantial satisfaction with the surgery results (Table 2); however,

TABLE 2. Participant-reported satisfaction and improvement in the Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial, Mtwara region, Tanzania.

Surgical outcome	n (%)	n (%)		
		Very satisfied with surgical outcome	Reported some improvement in ocular symptoms	Reported some improvement in daily life <sup>a</sup>
No upper eyelid problems	146 (34.0)	134 (91.8)	143 (98.0)	126 (87.5)
Mild postoperative trichiasis	107 (24.9)	89 (83.2)	104 (97.2)	92 (86.8)
Moderate to severe postoperative trichiasis	81 (18.9)	62 (76.5)	77 (95.1)	65 (82.3)
Mild eyelid contour abnormality	43 (10.0)	39 (90.7)	41 (95.4)	30 (69.8)
Moderate to severe eyelid contour abnormality	52 (12.1)	48 (92.3)	46 (88.5)	38 (73.1)
Overall	429 (100.0)	372 (86.7)	411 (95.8)	351 (82.8)

<sup>a</sup>% based on non-missing data; question not answered by five participants.

TABLE 3. Current ocular symptoms by surgical outcome in the Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial, Mtwara region, Tanzania.

Surgical outcome	At least one symptom, n (%)	Specific symptom, n (% within group) <sup>a</sup>				
		Blurred vision	Tearing	Feels lash(es) touching	Pain	Other <sup>b</sup>
No upper eyelid problem	49 (33.6) <sup>c</sup>	28 (19.3)	9 (6.2)	8 (5.5)	7 (4.8)	9 (18.8)
Mild postoperative trichiasis	47 (43.9)	18 (16.8)	14 (13.1)	21 (19.6)	1 (0.9)	5 (10.6)
Moderate to severe postoperative trichiasis	47 (58.0)	17 (21.0)	8 (9.9)	31 (38.3)	3 (3.7)	1 (2.1)
Mild eyelid contour abnormality	13 (30.2)	7 (16.3)	3 (7.0)	1 (2.3)	1 (2.3)	2 (15.4)
Moderate to severe eyelid contour abnormality	24 (46.2)	15 (28.9)	4 (7.7)	4 (7.7)	3 (5.8)	1 (4.2)
Overall	180 (42.0)	85 (19.9)	38 (8.9)	65 (15.2)	15 (3.5)	18 (10.1)

<sup>a</sup>Participants could report multiple ocular symptoms.

<sup>b</sup>Irritation, discharge and/or ocular discomfort.

<sup>c</sup>One participant indicated she was experiencing an eye problem, but did not indicate the specific symptom.

participants with postoperative TT were significantly less likely to report substantial satisfaction than those with ECA or no upper eyelid problems ( $p=0.001$ ). Over 95% of participants reported that surgery improved at least some ocular problems they experienced prior to surgery. Participants with ECA were less likely to report improvement in ocular problems than the other groups combined ( $p=0.04$ ). Over 80% of participants stated the surgery improved their daily life, and only two reported worsening in daily life. Participants with ECA were less likely to report improvement in daily life compared to the other groups ( $p=0.002$ ).

### Visual Acuity

Over 90% of participants stated their vision improved after surgery, with nearly 70% reporting a lot of improvement. Perceived improvement was similar across groups, ranging from 88% among those with moderate or severe ECA to 94% in those with no eyelid problems. Subjective improvement correlated well with change in visual acuity. Overall, 44% had visual acuity improvement of at least one line in one or both eyes, with 16% having this level of improvement in both eyes. Participants

were more likely to report a lot of improvement in their vision if they had experienced a one-line gain or more in visual acuity in one or both eyes ( $p=0.03$ ).

### Current Ocular Symptoms

Over 40% of participants reported at least one ocular symptom, with blurred vision being the most common (Table 3). Participants with unfavorable outcomes were more likely to report current ocular symptoms than those without an upper eyelid problem ( $p=0.01$ ). Participants with moderate or severe recurrence were most likely to report current ocular symptoms, followed by those with moderate or severe ECA. Feeling lashes touching the eye was the most common ocular symptom among participants with postoperative TT, while blurred vision was the most common ocular symptom reported by the group with ECA. Of the 13 participants without upper-eyelid TT who reported feeling lashes touching, six had lower-eyelid TT and two had moderate to severe ECA. Less than 5% of participants reported current ocular pain, and of those, 75% stated that surgery reduced the pain they had at baseline.

TABLE 4. Improvement in appearance following surgery, by surgical outcome in the Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial, Mtwara region, Tanzania.

Surgical outcome	<i>n</i> (%) <sup>a</sup>	
	Participant felt appearance had improved	Participant indicated household members noticed improvement in appearance
No upper eyelid problems	132 (91.7) <sup>a</sup>	108 (74.0)
Mild postoperative trichiasis	101 (94.4)	89 (84.0) <sup>a</sup>
Moderate to severe postoperative trichiasis	69 (85.2)	59 (72.8)
Mild eyelid contour abnormality	42 (97.7)	28 (65.1)
Moderate to severe eyelid contour abnormality	48 (92.3)	35 (67.3)
Overall	392 (91.8)	319 (74.5)

<sup>a</sup>Two participants indicated the eyelid surgery changed their appearance, but did not specify how it changed. One participant indicated a household member noticed a change in her appearance since the eyelid surgery, but did not describe the change.

## Appearance

Over 90% of participants felt that surgery improved their appearance (Table 4). Similarly, 75% reported members of the household noticing an improvement, and the correlation between the participant's perception and her report of the household's perception was moderately strong. Participants with moderate or severe recurrence were less likely to report improvement in their appearance than those with mild recurrence (85% vs 94%, respectively,  $p=0.04$ ), and also were less likely to report that household members had noticed improvement. Almost all participants with ECA reported improvement in their appearance; however, they were less likely to report that household members had noticed improvement than the other groups combined ( $p=0.04$ ).

## Perception of Surgery and Challenges

Only 6% of participants reported a complaint regarding the surgery. Postoperative TT was the most common complaint. Pain was reported by three individuals. When asked whether anything made having surgery difficult, 11% expressed challenges. Women were slightly more likely to report difficulties than men (12% vs 8%, respectively), with farming, cooking and lack of a caregiver being the most common problems.

## Future Surgical Participation

Almost 90% of participants ( $n=387$ ) stated they would undergo another operation if TT returned (Table 5). Participants who had moderate or severe recurrence were least likely to state that they would undergo repeat surgery ( $p=0.02$ ), followed by participants with ECA. Almost all participants stated they would recommend surgery to other TT patients. The main reason stated for not recommending

surgery to others was that participants believed others should make their own decisions.

## DISCUSSION

This study demonstrates differences in perceived surgical results, comparing individuals with an adverse surgical outcome, either TT or ECA, versus individuals with a successful surgical outcome. The areas of concern differed between individuals with postoperative TT and individuals with ECA. Participants with postoperative TT reported less overall satisfaction than participants with ECA or no upper eyelid problem. This finding is expected, since their reason for having surgery was not fully addressed. While surgery typically lessened TT severity in those with recurrence, participants with postoperative TT also were more likely to report tearing, feeling lashes touching their eye, and pain, consistent with the symptoms associated with TT. These participants also were less likely to feel their appearance had improved. In addition to the alteration in appearance related to entropion and trichiatric lashes, eyes with postoperative TT were more likely to have tearing and discharge, which likely is perceived as less attractive. Individuals with TT often try to minimize the pain associated with trichiatric lashes by keeping their eye closed, which also may affect appearance.

Participants with moderate to severe postoperative TT were least likely to state they would undergo repeat surgery. However, even within this group of 81 people, 80% reported that they would undergo repeat surgery. For the remaining 20%, given that their first surgery was not corrective, they may believe a repeat surgery will not help, and indeed recurrence following repeat surgery is more common than after initial TT surgery.<sup>15</sup> The vast majority of participants with moderate to severe postoperative TT (96%) would recommend surgery to others. This may be attributable to the fact that almost all of those with moderate to severe postoperative trichiasis reported that the

TABLE 5. Opinions about future surgery in the Partnership for the Rapid Elimination of Trachoma (PRET) surgery trial, Mtwara region, Tanzania.

Surgical outcome	<i>n</i> (%)	
	Would have repeat surgery if needed	Would recommend surgery to others <sup>a</sup>
No eyelid problems	137 (93.8)	143 (98.6)
Mild postoperative trichiasis	96 (89.7)	102 (95.3)
Moderate to severe postoperative trichiasis	65 (80.3)	78 (96.3)
Mild eyelid contour abnormality	37 (86.1)	42 (100.0)
Moderate to severe eyelid contour abnormality	45 (86.5)	52 (100.0)
Overall	380 (88.6)	417 (97.7)

<sup>a</sup>Two participants did not answer question.

initial surgery provided at least some improvement in their eye problems and nearly half benefited from at least one line of visual acuity improvement as well.

Participants with moderate/severe ECA were the least likely to report improvement in ocular symptoms, and blurred vision was the main symptom. While little is known about the long-term effects of ECAs on the ocular surface and eye health in general, there is biologic plausibility that ECAs can lead to reduced visual function resulting from anatomical defects that disrupt tear film production and distribution over the eye. Adequate tear film provides the most anterior refractive surface of the eye; hence, tear film irregularities can lead to large variations in refractive power and radial curvature.<sup>16</sup> Contour abnormalities also may affect the distribution and replenishment of the tear film, since consistent contact between the upper eyelid and globe during blinking may be impaired.<sup>17</sup> ECAs also can cause lagophthalmos due to misalignment of the eyelids upon closure or due to severe defects in the upper eyelid.<sup>8</sup> Proper eyelid closure is necessary to maintain the tear film and prevent dryness. Since the tear film also serves as an innate immune defense,<sup>18</sup> ECAs theoretically can increase the risk of ocular infection. Further research is needed in this area.

Participants with ECA were significantly less likely to report improvement in their daily life. The underlying cause of this reduced satisfaction cannot be determined from the data collected in this questionnaire. Interestingly, participants with ECA reported improvement in their appearance more often than those with recurrence. This finding likely is due to the fact that their lashes were no longer rubbing against their eyes, causing them to squint or keep their eyes closed, and they were less likely to have ocular discharge.

While we did observe differences in participants' perceptions based on surgical outcomes, it is important to note that over 90% of participants reported satisfaction with the surgery and the vast majority reported improvement in their vision. For most, surgery also led to improvement in ocular symptoms

and daily life. Participants stated improvement in their appearance following surgery and the majority reported they would undergo a further operation if their eye problem returned. Only a few participants expressed complaints regarding the surgery. Women expressed more difficulties with having surgery, stating that farming, cooking for their families, and lack of a caregiver were the most common difficulties.

This study has several strengths. Our results come from a large population within a single district that underwent surgery in a randomized clinical trial with strict oversight and management. All participants were treated and evaluated by the same study team. All surgical outcomes were recorded by the same trained observer and reviewed by senior team members, and all questionnaires were administered by a single trained interviewer. Standardized visual acuity measurements provided a tool for comparing participants' perception of their vision with an objective measure.

The study also has some limitations. We acknowledge the study was not undertaken from an anthropological perspective, but rather as an evaluation from the perspective of program implementation. Thus, specific details on the culture and environment of these respondents is not included, and might have enabled deeper understanding of responses. Because the questionnaire was only administered once during the trial, we were unable to determine if participants' perceptions changed over time. Also, while conduct of the questionnaire 2 years after surgery allowed for long-term perceptions about surgical outcomes, it is likely that problems related to the surgery itself were understated more so than issues related to long-term outcomes.

Given the high rate of postoperative TT and ECA, we found participants' responses to be more positive than we had expected. In Tanzanian culture, it is customary not to criticize others. Because the interviewers were associated with our study team, participants may have been hesitant to report negative perceptions. Thus, differences in perceived surgical outcomes across our groups may be understated, and

it is possible that more individuals were dissatisfied than they stated. However, we do not expect that different groups would be more or less likely to understate dissatisfaction. A prior study in Tanzania highlights the importance of engaging the entire community in any new project,<sup>19</sup> and in this study we worked with the full local community, including local health workers, the regional health bureau and individual community members.

As in any study of this sort, interviewer biases are possible. This can be particularly problematic if the interviewer is aware of the outcome status of the respondent, as it could lead to differential bias. To minimize the risk of bias related to our outcomes, the interviewer was not informed that we were planning to look at satisfaction across different surgical outcome types and was unaware of patient outcomes. Hence, in the event that there was interviewer bias, it would be systematic across all outcome types. Additionally, the majority of the questions were closed-ended and the interviewer was instructed to follow the questionnaire script exactly, without any deviation unless the participant needed further clarification. The project manager periodically observed the interviewer to ensure that study procedures were followed.

Surgical correction of TT is intended to preserve vision, and unfavorable outcomes, such as postoperative TT and ECA, can prevent achieving this goal. To our knowledge, the results of this study provide the first systematically-recorded evidence of how ECA impacts patients' lives, and they indicate that ECA is an important complication that needs adequate evaluation in surgical programs. We recommend that surgical programs systematically evaluate both postoperative TT and ECA across all surgical technicians. In addition, programs should incorporate more training on how to prevent both outcomes. A key aspect of this training should be adequate teaching in how to assess the immediate postoperative eyelid contour and make adjustments as necessary.<sup>20</sup>

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## DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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## REFERENCES

1. Resnikoff S, Pascolini D, Etya'ale D, et al. Global data on visual impairment in the year 2002. *Bull World Health Organ* 2004;82:844–851.
2. WHO. Report of the Second Meeting of the WHO Alliance for the Global Elimination of Trachoma. World Health Organization; 1998.
3. Reacher M, Foster A, Huber J. *Trichiasis surgery for trachoma: the bilamellar tarsal rotation procedure*. Geneva: World Health Organization: Programme for the Prevention of Blindness; 1993.
4. Reacher MH, Munoz B, Alghassany A, et al. A controlled trial of surgery for trichomatous trichiasis of the upper lid. *Arch Ophthalmol* 1992;110:667–674.
5. Bowman RJ, Faal H, Myatt M, et al. Longitudinal study of trichomatous trichiasis in the Gambia. *Br J Ophthalmol* 2002;86:339–343.
6. Rajak SN, Collin JR, Burton MJ. Trichomatous trichiasis and its management in endemic countries. *Surv Ophthalmol* 2012;57:105–135.
7. Merbs SL, Kello AB, Gelema H, et al. The trichomatous trichiasis clamp: a surgical instrument designed to improve bilamellar tarsal rotation procedure outcomes. *Arch Ophthalmol* 2012;130:220–223.
8. Gower EW, West SK, Cassard SD, et al. Definitions and standardization of a new grading scheme for eyelid contour abnormalities after trichiasis surgery. *PLoS Negl Trop Dis* 2012;6:e1713.
9. Gower EW, West SK, Harding JC, et al. Trichomatous trichiasis clamp vs standard bilamellar tarsal rotation instrumentation for trichiasis surgery: results of a randomized clinical trial. *JAMA Ophthalmol* 2013;131:294–301.
10. Bog H, Yorston D, Foster A. Results of community-based eyelid surgery for trichiasis due to trachoma. *Br J Ophthalmol* 1993;77:81–83.
11. Frick KD, Melia BM, Buhrmann RR, West SK. Trichiasis and disability in a trachoma-endemic area of Tanzania. *Arch Ophthalmol* 2001;119:1839–1844.
12. Dhaliwal U, Nagpal G, Bhatia MS. Health-related quality of life in patients with trichomatous trichiasis or entropion. *Ophthalmic Epidemiol* 2006;13:59–66.
13. Wolle MA, Cassard SD, Gower EW, et al. Impact of trichiasis surgery on physical functioning in Ethiopian patients: STAR trial. *Am J Ophthalmol* 2011;151:850–857.
14. Ferris III FL, Kassoff A, Bresnick GH, Bailey I. New visual acuity charts for clinical research. *Am J Ophthalmol* 1982;94:91–96.
15. Khandekar R, Al-Hadrami K, Sarvanan N, et al. Recurrence of trichomatous trichiasis 17 years after bilamellar tarsal rotation procedure. *Am J Ophthalmol* 2006;141:1087–1091.
16. Denoyer A, Rabut G, Baudouin C. Tear film aberration dynamics and vision-related quality of life in patients with dry eye disease. *Ophthalmology* 2012;119:1811–1818.



17. Bron AJ, Tiffany JM, Gouveia SM, et al. Functional aspects of the tear film lipid layer. *Exp Eye Res* 2004;78:347–360.
18. Akpek EK, Gottsch JD. Immune defense at the ocular surface. *Eye (Lond)* 2003;17:949–956.
19. McCauley AP, West SK, Lynch M. Household decisions among the Gogo people of Tanzania: determining the roles of men, women, and the community in implementing a trachoma prevention program. *SocSci Med* 1992;34:817–824.
20. Merbs SL, Harding JC, Cassard SD, et al. Relationship between immediate post-operative appearance and 6-week operative outcome in trichiasis surgery. *PLoS Negl Trop Dis* 2012;6:e1718.