

# Characteristics and perspectives of patients with postoperative trichiasis in Hadiya Zone, Ethiopia

Riju Shrestha<sup>a</sup>, Shannath L. Merbs<sup>b</sup>, Belay Bayissasse<sup>c</sup>, Alemayehu Sisay<sup>c</sup>, Colin Beckwith<sup>d</sup>, Paul Courtright<sup>d,e</sup> and Emily W. Gower<sup>a,f,\*</sup>

<sup>a</sup>Department of Epidemiology, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; <sup>b</sup>Department of Ophthalmology and Visual Sciences, University of Maryland School of Medicine, Baltimore, MD, USA; <sup>c</sup>Orbis International Ethiopia, Addis Ababa, Ethiopia; <sup>d</sup>Sightsavers, Haywards Heath, UK; <sup>e</sup>Kilimanjaro Centre for Community Ophthalmology, Division of Ophthalmology, University of Cape Town, South Africa; <sup>f</sup>Department of Ophthalmology, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

\*Corresponding author: Tel: +1(919) 966-1420; E-mail: egower@unc.edu

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**Background:** Postoperative trachomatous trichiasis (PTT) is a challenge for trichiasis surgery programs. Little is known about PTT patients' perceptions regarding outcomes and future disease management. This study aimed to understand the characteristics of PTT patients, how they managed trichiasis and their perceptions of prior surgeries and future surgery uptake.

**Methods:** Patients with PTT were identified during an existing trichiasis screening program in Hadiya Zone, Ethiopia. A vision assessment and evaluation of the eyelids were conducted to determine distance vision, presence and severity of trichiasis and eyelid contour abnormalities. A questionnaire was administered to obtain information regarding patients' perceptions of surgery and PTT management approaches. Descriptive statistics were used to characterize PTT and determine associations between PTT severity and patient perceptions.

**Results:** Among 404 participants, most were female (79.7%) and aged 40–60 y (62.6%). In total, 514 eyelids had PTT, and nearly half had severe PTT (46.9%). Although >50% of participants were currently epilating to manage their PTT, the majority (82.8%) indicated that they wanted repeat surgery. Most participants indicated that pain persisted despite epilation. The majority (75.1%) indicated satisfaction with their prior surgery and 59.6% indicated that they would recommend surgery to others.

**Conclusions:** This study, which included a large proportion of severe PTT cases, indicated that individuals were generally satisfied with prior surgery and would prefer to have surgery again for PTT management.

**Keywords:** epilation, postoperative trachomatous trichiasis, surgical outcome, trachoma, trichiasis.

## Introduction

Trachoma is an infectious eye disease caused by the bacterium, *Chlamydia trachomatis*. Repeated infections lead to scarring of the eyelid, which can turn the eyelid inward, such that the eyelashes rub against the eye. This condition is known as trachomatous trichiasis (TT). The WHO recommends the 'SAFE' strategy for elimination of trachoma: Surgery for trichiasis; Antibiotic treatment for infection; Facial cleanliness; and Environmental improvement to reduce transmission.<sup>1</sup> Surgery is the preferred treatment strategy for TT, during which the affected eyelid is incised, rotated and sutured to return the eyelashes to their normal anatomic position.<sup>2</sup> However, in some cases, the eyelid

may not be adequately corrected during surgery, such that the patient still has TT after surgery or the TT recurs in the months or years after surgery. These two conditions are classified as post-operative TT (PTT).

PTT remains an important problem for most trachoma control programs. Rates of PTT vary widely, ranging from 10% to >50% within 2 y after surgery.<sup>3-10</sup> The WHO recommends that patients with PTT should be managed by highly trained practitioners; however, there are no specific guidelines regarding how to manage these patients.<sup>11</sup>

Poor surgical outcomes like PTT are believed to be a reason why TT surgery uptake is low in some communities. 10,12,13 However, systematic data on clinical characteristics and the

Classification	Definition
PTT severity	
Mild	1-4 eyelashes touching globe, no epilation OR
	<1/3 of eyelashes epilated, no eyelashes touching globe
Moderate	5-9 eyelashes touching globe, no epilation OR
	1–4 eyelashes touching globe and >1/3 of eyelashes epilated
Severe	5–9 eyelashes touching globe and <1/3 of eyelashes epilated OR
	≥10 eyelashes touching globe, regardless of epilation status OR
	>1/3 of eyelashes epilated, regardless of eyelashes touching globe
Eyelid contour abnormality	
Mild	Vertical deviation from the natural contour,1 mm in height (less than half the pupil height in sunligh and affecting <1/3 of horizontal eyelid length
Moderate	Vertical deviation from the natural contour 1–2 mm in height (about the pupil height in daylight) or affecting 1/3–2/3 of horizontal eyelid length
Severe	Vertical deviation from the natural contour >2 mm in height (more than the pupil height in daylight or a defect >2/3 of the horizontal eyelid length

perspectives of patients' experiencing PTT continue to be limited. For example, in a study aimed at understanding patient satisfaction with initial TT surgery in rural Tanzania, participants with PTT reported less satisfaction than those without PTT.<sup>13</sup> Further, when participants were asked whether they would undergo repeat surgery if their condition returned, individuals with PTT or eyelid contour abnormality (ECA) were less likely to want repeat surgery than those with a good outcome. Those with moderate or severe PTT were less likely to want repeat surgery than those with mild PTT. No study has specifically focused on understanding patient preference for PTT management. Hence, the primary goals of this study were to describe clinical characteristics of eyes in patients experiencing PTT and to determine patient perspectives on TT and PTT management.

#### Methods

This observational study was conducted in the Hadiya zone in the Southern Nations, Nationalities and Peoples Region of Ethiopia from March 2017 to July 2018, in conjunction with the Maximizing Trichiasis Surgery Success (MTSS) trial. 14 The MTSS trial sought to evaluate three TT surgery approaches among surgery-naïve eyelids with TT. The MTSS trial recruited participants through two methods: door-to-door case finding and centralized screenings conducted following community announcements. Trained door-to-door case finders identified individuals that they suspected had TT and asked them to present for final screening by MTSS study personnel at a central location. Community mobilizers made announcements at local markets, religious activities and other community gatherings, indicating that an eye screening would be held, and anyone with eye problems could come for evaluation. At these screenings, individuals with TT were directed to meet with our study team for further assessment and to discuss TT management. If an individual had unoperated TT, they were invited to participate in the MTSS trial. If instead they had PTT, they were invited to participate in the current observational study. For the current study, individuals were eligible for this study if they were aged ≥18 y, had at least one prior TT surgery and had upper eyelid PTT defined as at least one eyelash touching the eye or evidence of epilation following surgery. Eligible individuals were directed to meet with the study team, who described the study, invited them to participate and obtained informed consent. Consenting participants completed a questionnaire about the timing of their prior surgery, perceptions of prior surgery and outcomes and future management preferences.

A trained integrated eye care worker (IECW) conducted an eye examination to assess the eyelid for PTT and surgical outcomes, including extent of epilation, number and location (nasal, central, temporal) of trichiatic eyelashes, as well as the presence and severity of ECA. 15 Corneal opacity was also assessed using a standard grading scheme.<sup>16</sup> We measured distanced visual acuity for both eyes monocularly using Peek Acuity software (https:// www.peekvision.org/, Berkhamsted, UK) on a smartphone at 2 m. moving to 1 m as needed. Cause of vision loss was not included in the assessment. The IECW used a high-resolution smartphone camera to obtain three images of each eyelid: the participant looking up to visualize the upper eyelid margin; at a 45-degree angle offset from center to view the thickness of the eyelid; and with the eyelid everted to capture the surgical scar. A study team member reviewed the images to assess ECAs and other characteristics.

At the eye level, we categorized PTT severity using the same approach as our previous studies, which incorporates the number and location of eyelashes touching the globe (nasal, central, temporal) and location and extent of epilation, and we characterized ECAs based on a standardized grading scheme (Table 1). 4,14,15 We grouped nasal and temporal trichiasis as peripheral. For each eye, we categorized presenting distance visual acuity using the WHO definitions: normal (Snellen 6/18 or better), impaired

Characteristic	N (%)
Female	322 (79.7
Age category (y)	
18-39	98 (24.3)
40-60	253 (62.6
>60	53 (13.1)
Visual acuity (best eye, presenting)*	
Normal (6/18 or better)	233 (59.6
Impaired (<6/18-3/60)	113 (28.9
Blind (<3/60)	45 (11.5)
Time since most recent surgery*	
<1 y	47 (11.6)
1–3 y	128 (31.7
>3 y	226 (55.9

(Snellen <6/18 to 3/60) and blind (<3/60).<sup>17</sup> At the participant level, we categorized individuals based on PTT severity in their worse eve.

We used descriptive statistics to characterize the study population. We summarized categorical variables with frequencies and percentages. We first summarized all responses for the participant questionnaire survey and then further dichotomized some responses to determine any associations between the participant responses and PTT severity. The associations were assessed using  $\chi^2$  test. We conducted analyses using SAS software, version 9.4 (SAS Institute Inc., Cary, NC, USA).

## Results

We invited 404 individuals to participate, and all consented to participation. A total of 147 (36.4%) participants had prior bilateral and 257 had prior unilateral surgery, resulting in 551 eyelids with prior TT surgery. Demographics were similar between bilateral and unilateral surgery patients. Among the participants, 322 (79.7%) were females, 253 (62.6%) were aged 40–60 y, 226 (55.9%) had their most recent surgery >3 y prior to the survey and 158 (60.4%) participants had visual impairment or were blind in at least one eye (Table 2).

## Characteristics of eyes with prior surgery

Among the 147 participants with prior bilateral surgery, 110 (74.8%) had PTT in both eyes at the time of the study visit. Of the remaining 37 participants with prior bilateral surgery, the proportion of left and right eyes with PTT was fairly similar (left eye=13.6% and right eye=11.6%). Of the 257 participants with prior unilateral surgery, 135 (52.5%) had prior right eye surgery and 122 (47.5%) had prior left eye surgery. Interestingly, only three of these individuals developed incident TT in their other (unoperated) eye. Thus, a total of 514 eyes had PTT, of which 46.9%

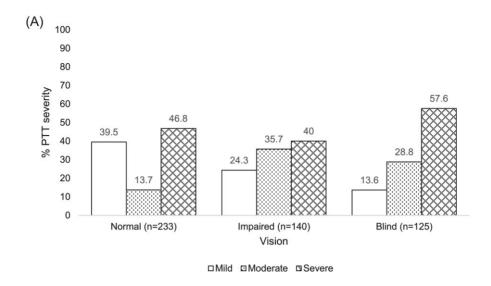
**Table 3.** Characteristics of 514 eyes with postoperative trachomatous trichiasis (PTT)

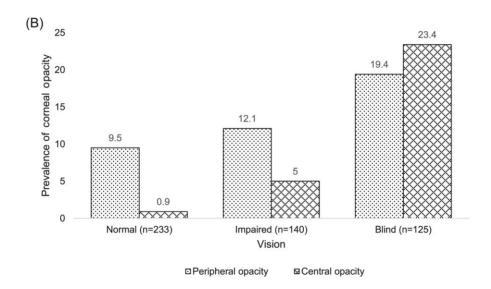
Characteristic	N (%)
Number of trichiatic eyelashes	
None (epilating only)	60 (11.7)
1-4	332 (64.6)
5–9	90 (17.5)
10+	32 (6.2)
Epilation	
None	202 (39.3)
<1/3 of eyelid	91 (17.7)
1/3 to 2/3 of eyelid	54 (10.5)
>2/3 of eyelid	167 (32.5)
PTT severity	
Mild	151 (29.4)
Moderate	122 (23.7)
Severe	241 (46.9)
PTT location(s)	
Central only	105 (20.4)
Peripheral only	151 (29.4)
Central and peripheral	258 (50.2)
Eyelid contour abnormality	
None	469 (91.4)
Mild	17 (3.3)
Moderate	21 (4.1)
Severe	6 (1.2)
Section of eyelid margin missing	14 (2.7)
Distance visual acuity	
Normal (6/18 or better)	233 (46.8)
Impaired (<6/18-3/60)	140 (28.1)
Blind (worse than 3/60)	125 (25.1)
Gap between eyelid and eye when eye is open	20 (3.9)
Lagophthalmos	1 (0.2)
Abnormally thick eyelid	22 (4.3)
Corneal scar	
None	406 (79.3)
Peripheral opacity	64 (12.5)
Central opacity	42 (8.2)

Missing data: eyelid contour abnormality (n=1), section of eyelid margin missing (n=1), visual acuity (n=16), gap between eyelid and eye (n=1), abnormal eyelid thickness (n=2), eyelid margin missing (n=1), corneal scar grade (n=2).

had severe PTT (Table 3). The majority of the severe PTT cases had trichiatic eyelashes touching the globe in all three locations. For PTT cases that had trichiatic eyelashes either centrally or peripherally, but not both, peripheral trichiatic eyelashes were more common, regardless of PTT severity. In 312 eyes (60.7%), both PTT and evidence of recent epilation were noted. Only 8.6% of PTT eyes had an ECA.

While 53.2% of eyes were visually impaired or blind, only 8.2% of eyes had a central corneal opacity. There was an association between increased PTT severity and reduced distance vision (p<0.001, excluding 16 eyes missing vision data), although





**Figure 1.** (A) Relationship between vision loss and PTT severity. Missing data: visual acuity (n=16). (B) Relationship between vision loss and corneal opacity. Missing data: visual acuity (n=16); corneal scar (n=2).

this was not always due to the presence of a corneal opacity (Figure 1).

# **Prior surgery details**

The majority of participants reported receiving their prior TT surgery at the nearest health center. Health extension workers and village leaders were the primary sources of information for learning about surgery availability (Table 4). Approximately half of the participants knew another individual who had previously undergone TT surgery. There were no differences in responses by men and women.

Epilation was commonly used for trichiasis management prior to surgery; 87.2% of participants reported using epilation to man-

age their TT before their prior surgery. When participants were asked about their reasons for seeking their prior surgery, the vast majority stated pain was the primary reason, while only 8.0% stated fear of vision loss. Most participants mentioned that their vision improved after surgery.

# Participant preferences for PTT management

Despite having PTT, the majority of participants reported being satisfied with their prior surgery outcome. Individuals with severe PTT were less likely to report satisfaction than those with mild PTT (66.1% vs 75.8%; p=0.07), although the difference was not statistically significant. Satisfaction was more common among participants that reported their condition improved

Table 4. Participant survey responses	
Question	N (%)
Location of most recent TT surgery	
Health center	345 (86.3)
Health post (patient's community by outreach)	33 (8.3)
Government hospital	20 (5.0)
Neighboring community (outreach)	2 (0.5)
Number of times sought surgery before receiving it	
1	312 (77.8)
2	68 (17.0)
3+	21 (5.2)
Prior to surgery, knew someone else who had	229 (57.4)
TT surgery	
Source of information about the surgery service*	
Health extension workers/Health	129 (32.1)
Development Army	
Kebele/village leader	115 (28.6)
Spouse	84 (20.9)
Child living in household	59 (14.7)
Friend/neighbor	26 (6.5)
Previously operated patient	22 (5.5)
Other	3 (0.7)
Method for managing TT before surgery*	2 ( 6 ( 0 7 2 )
Epilation	346 (87.2)
Nothing	40 (10.1)
Plant-/animal-based topical treatment	11 (2.8)
Religious prayers Reasons presented for surgery*	4 (1.0)
Pain/relief from trichiasis	368 (91.5)
Feared vision loss	32 (8.0)
Believed it will restore vision	5 (1.3)
Someone convinced me to do it	4 (1.0)
Regain ability to work	2 (0.5)
Other	1 (0.3)
Examined at the health service after sutures	297 (74.4)
removed	
Comparison of current vs preoperative pain	
Pain is reduced but still present	243 (60.5)
Pain is gone	143 (35.6)
No change	9 (2.2)
Worse	7 (1.7)
Self-reported change in vision after surgery	
Improved	333 (83.0)
Worsened	54 (13.5)
No change	14 (3.5)
Perceived change in condition after surgery	
Improved	339 (85.0)
Worsened	55 (13.8)
No change	5 (1.3)
Satisfied with the surgery outcome	298 (75.1)
Recommended TT surgery to someone else	237 (59.6)
Recommended to someone not to have TT	16 (4.0)
surgery	

Table 4. Continued	
Question	N (%)
Currently feels pain from eyelashes	357 (89.5)
Desired management for PTT*	
Have surgery again	333 (82.8)
Epilation	28 (7.0)
Nothing	25 (6.2)
Plant-/animal-based topical treatment	6 (1.5)
Burn/melt lashes	2 (0.5)
Other	9 (2.2)
Desired location for PTT management	
Health center	321 (93.9)
Government hospital	10 (2.9)
Health post (patient's community by outreach)	8 (2.3)
Neighboring community (outreach)	1 (0.3)
Other	2 (0.6)

Abbreviations: PTT, postoperative trachomatous trichiasis; TT, trachomatous trichiasis.

Note, missing data: most recent TT surgery location (n=4), number of times you tried to have surgery before receiving it (n=3), knowledge of others who had already had TT (n=5), where did you hear about surgery (n=2), how did you manage your condition before surgery (n=7), why did you present for surgery (n=3), examination after sutures removed (n=5), comparison of pain before and after surgery (n=2), vision change after surgery (n=3), condition change after surgery (n=5), satisfied with surgery outcome (n=7), recommended TT surgery to someone else (n=6), recommended that someone not have TT surgery (n=2), pain from eyelashes (n=5), preferred future PTT management (n=2), where do you want your current trichiasis to be managed (n=62).

 $^*$ The total for these three questions is >100% because participants were allowed to report multiple responses.

after surgery compared with those that did not (77.6% vs 53.9%, p<0.001).

At the time of our study visit, 56.9% of participants (60.7% of eyes) were epilating to manage their PTT. When asked how they would prefer their PTT managed, among those who were epilating, 84.7% said they wanted surgery and 7.8% wanted to continue epilation. These numbers were similar to the overall study population, where 82.8% indicated they wanted to repeat surgery. Similar to their initial surgical site (primarily at a health center), most participants preferred additional surgery to be performed at the health center.

Approximately half of all participants reported recommending surgery as a treatment option to other individuals. Participants who were satisfied with the surgery outcome were more likely to recommend surgery to others compared with those who were not satisfied (70.8% vs 24.5%; p<0.001). Sixteen participants (4.0%) mentioned previously telling someone not to have the surgery, and the primary reason for not recommending surgery was their own PTT (9 of 16 responses).

## **Discussion**

Within this study of 404 individuals who presented for an IECW to evaluate their eye condition, the majority (71.6%) had moderate or severe PTT and 79.6% had peripheral trichiatic eyelashes. Our finding that peripheral PTT is common is consistent with a prior analysis of four clinical trials that showed peripheral PTT was more common than central PTT for both of the commonly used TT surgery procedures. Approximately 4% had a gap between the eye and eyelid when the eyelid was open, while only one had lagophthalmos. This frequency of lagophthalmos is also consistent with prior studies. Gaps between the eye and eyelid, however, have not been systematically reported previously. Similar to many previous studies, most participants were females and aged 40–60 v. 3,4,6,7,9

The prevalence of severe PTT in our study (46.9%) is high in comparison with prior studies aimed at evaluating TT surgery outcomes. <sup>18-21</sup> This difference may be a result of our study design, given that participants were individuals who were identified as having TT by a case finder or self-selected to be screened by an IECW. These individuals likely have worse outcomes from their prior surgery compared with the general surgery population. Eligibility criteria for the study required that participants have PTT. Thus, the data from this study do not provide information on the prevalence of PTT in the region and should not be misinterpreted to represent the rate and severity of PTT in the area.

Among participants with prior bilateral surgery, 74.8% had PTT in both eyes, while only three participants (0.7%) with prior unilateral surgery developed TT in their contralateral (previously unoperated) eye. Prior studies have shown that preoperative TT severity, surgical quality and disease progression all contribute to PTT.<sup>22,23</sup> In this study, we did not have access to preoperative data. Thus, it is not possible to account for the preoperative TT severity in our analyses, and it is difficult to know whether the high concordance of PTT between eyes of bilateral cases is a result of ongoing disease progression or because the same surgeon performed surgery on both eyes, and the surgical quality and PTT is reflective of that. However, the lack of incident TT in contralateral eyes of unilateral surgery participants suggests that surgical quality likely is a driving factor in the high rate of bilateral PTT in this study.

Less than 10% of previously operated eyes had an ECA. This is likely due to the fact that ECAs typically develop as a result of surgical overcorrection, while PTT is more likely when an eyelid is undercorrected during surgery. The low proportion of ECAs seen in eyelids with PTT in our study is similar to a prior study, where only 47 (9.1%) out of the 518 participants had both PTT and an ECA. 13

Even although all participants had PTT, 85% felt their condition improved after their prior surgery. Most indicated that they wanted repeat surgery at the same location as their prior surgery, suggesting that despite poor outcomes, they would seek surgical services in the community again. Previous focus group participants, however, have been explicit about the need to have better surgeons in the community. More than half recommended TT surgery to others, and participants who were satisfied with their surgical outcome were more likely to recommend surgery to others. Although the proportion of participants recommending TT surgery is low compared with findings from a prior surgery

trial, both studies' results indicate that participants are more likely to recommend surgery when their condition improved following surgery. This finding has important implications for future TT management programs given that the uptake of recommended surgery is an important issue. 12,25,26 In high TT-burden settings, patients who are satisfied with the surgical outcome and willing to recommend surgery to others could be used to further encourage TT patients to seek management. By contrast, a recent study showed that only 19% of individuals with TT who had heard rumors of poor surgical outcomes were willing to have surgery compared with 60% who had not heard about poor outcomes, underscoring the importance that TT surgery quality has on surgical uptake. 24

The primary reason participants sought previous surgery is for pain management, and only a few participants reported fear of vision loss as a motivating factor. While we did not specifically differentiate between initial and repeat surgery in eliciting this information, we assume that individuals with PTT seek repeat surgery for pain management. Our results are similar to a prior study conducted in Gambia that identified eye pain as the main factor patients sought TT surgery.<sup>27</sup> Interestingly, although vision loss was common in our study population, only a small proportion of individuals (8.2%) had central corneal opacity, suggesting cataract and other conditions may be the primary causes of vision loss in this cohort of individuals with PTT. However, trichiasis is known to reduce vision even in the absence of corneal opacity, possibly as a result of excess tearing, and research has shown that TT surgery improves quality of life, regardless of whether vision changes after surgery. 13,28

In this community-based screening setting epilation was common, with >60% of participants reporting epilation to manage their PTT. This finding is similar to another study in Ethiopia that reported 75% of individuals with TT were epilating at the time of examination. In that study and ours, more than half of those who were epilating reported that they were interested in having surgery to correct their TT. This is in contrast to a longitudinal study of epilation and a clinical trial (both among eyes with mild TT), in which most individuals preferred to keep epilating. However, even in those studies, >70% of individuals indicated they would seek surgery if their disease progressed.<sup>29,30</sup>

This study has some limitations. Although participants were recruited during community-based TT screening, it is likely that not all PTT patients living in the area attended the screening campaigns; individuals with less severe PTT or who were not satisfied with their prior surgery experience may not attend community-based screening events. Additionally, the survey did not ask questions related to esthetics. Thus, this study may not fully capture perspectives of all individuals with PTT. This study has several strengths. Participants were recruited during community-based screening, and most participants received surgery in a programmatic setting instead of a clinical trial, making the findings from this study generalizable to a broader population. Finally, our use of standard definitions for ECA and TT severity permit comparison across studies.

#### Conclusion

In conclusion, the majority of participants in this study desired repeat surgery to correct their PTT, and the driving factor for prior surgical treatment was pain relief. Current epilation practices did not deter interest in surgery. This study also shows that individuals with major TT expressed interest in having repeat surgery, despite poor prior outcomes. This highlights the importance of health services maintaining access to free, high-quality surgery as the backlog of TT cases is addressed.

**Authors' contributions:** EWG, PC and SLM conceived and designed the study. EWG, BB, PC and CB developed the data collection tool. BB, AS and EWG implemented the study. RS conducted the data analysis. RS, EWG and PC drafted the manuscript. RS, SLM, EWG, AS, BB, CB and PC revised the manuscript for intellectual content. All authors read and approved the final version of the manuscript.

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Competing interests: None declared.

**Ethical approval:** The Southern Nations Nationalities and Peoples' Regional State Health Bureau and the Institutional Review Board at the University of North Carolina at Chapel Hill approved the study. The study adhered to the principles of the Declaration of Helsinki, and all participants provided written informed consent before participation. Patients with trichiasis were referred for management.

Data availability: Data are available upon request.

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