

1 Trachomatous Trichiasis (TT) management in Tanzania: a mixed method study
2 investigating barriers and facilitators to obtaining treatment
3 Rebecca M. Flueckiger^{1*}, George Kabona², Upendo Mwingira^{2,#3}, Alistidia Simon², Jeremiah Ngondi³

4 1. RTI International, Atlanta, GA, USA

5 2. Neglected Tropical Disease Control Program , Ministry of Health Community Development
6 Gender Elderly and Children, Dar es Salaam , Tanzania.

7 3. RTI International , Dar es Salaam , Tanzania

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9 *Corresponding author

10 Email: rflueckiger@rti.org

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16 Abstract

17 Background: Prolonged ocular Chlamydial infection, known as trachoma, can lead to trichomatous
18 trichiasis (TT). TT is the stage of trachoma where the eyelid turns inwards, resulting in lashes rubbing
19 against the cornea. TT can damage the cornea, leading to vision impairment or blindness. Treatment for
20 TT includes epilation or surgery. Trachoma is targeted for elimination as a public health problem. One
21 criterion of trachoma elimination is less than 0.2% prevalence of TT unknown to the health system in
22 adults \geq 15 years. There are several districts in Tanzania that have not attained this target.

23 Methodology: We selected six districts across three regions in Tanzania. Our mixed-methods approach
24 included a retrospective review and analysis of program data and implementation of key informant
25 interviews (KII) and focus group discussions (FGD).

26 The desk review collated data on district-level indicators and generated estimates around number and
27 proportion of cases not identified by case finders and cases lost along the continuum of care. KIIs and
28 FGDs guides were structured to enlist responses around case finding techniques, linkage to services and
29 TT surgery process.

30 Conclusion: We found a substantial proportion (13%) of TT positive people were not being identified by
31 case finders, and of those identified, majority (72%) were lost along the continuum of care. These
32 factors likely contribute to high TT prevalence in districts where surgical interventions are ongoing.

33 Engaging community leaders to share TT information and enlisting people who have received surgery to
34 witness in communities may encourage consent of examination by case finders and increase surgical
35 uptake. After witnessing positive effects of surgery, many interviewees who had previously declined
36 surgery changed their mind. Increasing frequency of surgical camps would improve access to these
37 populations. Additionally, giving more notice about surgical camps and extending duration is important
38 to enable remote populations to obtain services.

39 Author Summary

40 Treatment for trachomatous trichiasis (TT) includes epilation or surgery. There are several districts in
41 Tanzania that have struggled to link people with TT to services. It is important for the program to
42 understand why this is the case to inform program adaptations for improved linkage to services. We
43 implemented a mixed methods approach to address this knowledge gap. We found a large portion of TT
44 positive people are not being identified by case finders and of those identified, many are lost along the
45 continuum of care. These factors are likely contributing to the unexpectedly high TT prevalence in
46 districts where surgical interventions are ongoing. Barriers to identifying cases included remoteness,
47 case finder credibility, knowledge of TT, and case finder motivation. Once cases are identified, the
48 largest gap along the continuum of care is the link between being identified and screened. We found
49 barriers to attending screenings and subsequently obtaining treatment to be fear of surgery, distance
50 from surgical camps, agricultural season, time to plan, awareness and frequency of camps, and lack of
51 assistance after surgery.

52

53 Introduction

54 Prolonged conjunctival infection with *Chlamydia trachomatis* leads to an inflammatory response,
55 trachomatous inflammation–follicular (TF) and trachomatous inflammation-intense. Overtime, cycles of
56 repeated infection can progress to scarring of the conjunctiva, causing entropion inward turning of the
57 eyelid and resulting in lashes rubbing against the cornea. This painful stage of the disease is called
58 trachomatous trichiasis (TT). TT can damage the cornea, leading to vision impairment or blindness [1, 2].
59 Trachoma is targeted for elimination as a public health problem[3]. One criterion of trachoma
60 elimination is prevalence of TT unknown to the health system of less than 0.2% in adults 15 years and
61 older [4]. “Unknown to the health system” are cases that have not previously been operated on, not
62 previously refused treatment, or have not been referred for treatment [5]. District-level prevalence is
63 estimated through population based prevalence surveys [6] and these prevalence estimates are used as
64 a guide for planning interventions [7, 8]. Studies have shown that TT surgery results in improved vision
65 and physical function [9] as well as reduced photophobia and pain [10]. The World Health Organization
66 (WHO) recommends a bilamellar tarsal rotation procedure to correct entropion caused by TT [11]. While
67 not recommended by WHO, epilation is commonly practiced to manage minor TT and may lower risk of
68 corneal opacity [12, 13]. Regardless of vision loss, untreated TT has been shown to significantly reduce
69 quality of life [14, 15].

70 Linking TT positive people to TT surgery is a major concern in trachoma endemic settings. In Tanzania, TT
71 surgery is provided free of charge and surgery programs are active in six regions (Mtwara, Pwani,
72 Dodoma, Arusha, Manyara, and Lindi). The continuum of care for TT is the following: 1) Case finders
73 identify a positive TT case, 2) Eye care professionals screen the identified case, 3) TT surgeons confirm
74 the screened case, and 4) Treatment is provided.

75 In 2016, the TT backlog in Tanzania was estimated to be 214,800 [16], and in 2017, only 2,120 people
76 were reported to have received surgery [17]. This equates to less than 1% of people needing surgery
77 receiving it. In 2018 surveys were conducted in Mtwara, Dodoma, and Lindi which demonstrated
78 continued TT prevalence above the elimination threshold. It is important for the trachoma programs to
79 understand why TT elimination targets are not being achieved to inform program adaptations for
80 improving access to services. We implemented a mixed methods approach to better understand why
81 trachoma impact surveys in Tanzania are demonstrating unexpectedly high prevalence of TT in
82 communities where TT surgical intervention is ongoing and how this challenge could be addressed.

83 **Methods**

84 Our conceptual framework is a mixed methods approach which includes a retrospective review and
85 analysis of program data and implementation of key informant interviews (KII) and focus group
86 discussions (FGD).

87 **Sample selection**

88 The regions of Dodoma, Lindi, and Mtwara demonstrated different levels of success in achieving TT
89 elimination thresholds. We selected two districts in each of the three regions. The number of surgeries
90 performed in each of these districts (in 2018 for the districts in Dodoma and Lindi and in 2016 for the
91 districts in Mtwara) was used as an indicator for selecting districts to include in this study. We selected
92 districts with the highest number of surgeries, as conducting many surgeries suggests that the program
93 was active for an entire year (or close to it) rather than only conducting a few surgical camps over the
94 course of one or two months. The districts selected were Bahi and Chamwino in Dodoma, Liwale and
95 Ruangwa in Lindi, and Newala and Tandahimba in Mtwara.

96

97 The review of program data collated information on 8,834 people from case search registries, screening
98 registries, TT surgery logs, and supervision reports across the six districts (Table 1). The sample was not
99 meant to be generalizable, but rather to provide insight into the situation within these specific
100 geographies as a supplement to the KIIs and FGDs.

101 *Table 1. Program data sample*

Region	District	Number of cases		
		Female	Male	Total
Dodoma	Bahi	1,508	559	2,067
Dodoma	Chamwino	686	238	924
Lindi	Liwale	735	474	1,209
Lindi	Ruangwa	1,663	913	2,576
Mtwara	Newala	465	148	613
Mtwara	Tandahimba	1,014	431	1,445
Grand total		6,071	2,763	8,834

102
103 The qualitative component of this study involved selecting TT positive people who had received surgery,
104 TT positive people who had not received surgery, TT case finders (who are typically members of the
105 community they work in), TT surgeons, and district-level health officers from the six selected districts.
106 Sample size estimates for qualitative studies often rely on theoretical saturation which cannot be
107 determined prior to beginning the study. Because of this, previously published estimates were used to
108 inform the sample size [18, 19] (Table 2). The TT positive people and the case finders were purposively
109 selected from the program data while considering distributions by ward. The ward was considered in
110 order to ensure representation from different communities in the districts. A random selection of case
111 finders for FGDs was made in each district. Each of the six districts had one active TT surgeon, and so
112 this individual was interviewed in each district. The district-level health officers were selected based on
113 their level of involvement during program implementation. In all districts, the district eyecare/NTD
114 coordinators were interviewed. No incentives were provided for participating in these KIIs and FGD, and
115 no recruited person declined to participate.

116 *Table 2. Qualitative sample*

Region	District	Persons with TT who received treatment			Persons with TT who did not receive treatment			Case finders (FGD)	Surgeons	District-level health officers
		Female	Male	Total	Female	Male	Total			
Dodoma	Bahi	7	6	13	7	3	10	10 (1)	1	1
Dodoma	Chamwino	5	5	10	5	5	10	10 (1)	1	1
Lindi	Liwale	5	6	11	5	4	9	10 (1)	1	1
Lindi	Ruangwa	5	5	10	5	5	10	8 (1)	1	1
Mtwara	Newala	6	4	10	5	5	10	8 (1)	1	1
Mtwara	Tandahimba	6	4	10	5	5	10	10 (1)	1	1
Grand total		34	30	64	32	27	59	56 (6)	6	6

117

118 The Interviewers and FGD facilitators were experienced in conducting qualitative studies and who are
 119 familiar with the cultural background of the study area and spoke Kiswahili fluently. Prior to the field
 120 work the interviewers and facilitators were trained by the local primary investigator on the protocol,
 121 interview guides and discussion guides.

122 **Analysis**

123 **Quantitative**

124 All quantitative analyses were performed in R v3.4.4. From the program data, we first estimated the
 125 number of TT cases in each district (backlog) as;

126
$$Prevalence_{TT} * Population_{\geq 15\ years} = TT\ backlog.$$

127 TT prevalence was provided by the NTD control program Ministry of Health, Community Development,
 128 Gender, Elderly, and Children (MoHCDGEC) (Table 3Table 3), and population estimates were calculated
 129 using methods described in detail elsewhere [16]. Briefly, district-level population was estimated from
 130 www.worldpop.org raster files [20] using the zonal statistics tool in ArcGIS 10.3[21] and then multiplied
 131 by the population percent expected to be 15 years and older derived from the UN population division
 132 (UNdata)[22] rural population pyramids.

133 *Table 3. TT prevalence estimates*

Region	District	TT prevalence	Population (15 years and older)
Dodoma	Bahi	1.07% (2018)	136,599
Dodoma	Chamwino	0.28%/0.47% (2018)*	198,126
Lindi	Liwale	0.69% (2018)	58,599
Lindi	Ruangwa	0.92% (2017)	104,729
Mtwara	Newala	0.28% (2018)	143,004
Mtwara	Tandahimba	0.72% (2018)	173,056

*split into North and South Chamwino evaluation units for 2018 surveys

134

135 We next explored the continuum of care and determined the month each step along the continuum
136 occurred, time lag between each step (estimating the median and interquartile range (IQR)), and
137 proportion of cases that drop out before surgery and where along the continuum this occurred. To
138 estimate the number of positive cases lost between being identified by case finders and screened, we
139 assume that those who did not attend screening similar to those who did. We estimated the number of
140 positive cases lost between identification and screening as

141
$$x(y * z) = N. screen lost_{positive},$$

142 where x is percent confirmed positive, y is percent lost before screening, and z is number identified by
143 case finders.

144 With these findings, we estimated the proportion of the TT backlog lost along the continuum of care by
145 multiplying the dropout proportion at each step by the total backlog. We then calculated the number of
146 cases not identified by case finders as

147
$$TT\ backlog - (N. confirmed_{positive} + N. screen\ lost_{positive}) = TT\ cases_{unidentified}.$$

148 Finally, we ran regression models to determine significance of association between cases being screened
149 and district, sex, and month of identification, as well as association between cases treated and district.

150 The quantitative estimates are not meant to draw broad conclusions. These estimates are illustrative
151 and give a general idea of the magnitude of gaps along the continuum of care.

152 Qualitative

153 All qualitative analyses were performed in Atlas.ti v8.1.28.0. A qualitative code book was developed a
154 priori representing key constructs. These included: case finding techniques, linking identified cases to
155 services, and surgery process. The guides also capture information on age, employment, and time of
156 year when surgery was offered. Interviews were audio recorded, translated into English, and transcribed
157 verbatim. The transcribed KIIs and FGDs were organized and coded according to the code book. When
158 new themes were identified, additional codes were added. Key themes were developed and organized
159 around the study objectives. We have provided participant quotes to illustrate the themes.

160 Ethics

161 This study was approved by the National Institute for Medical Research of Tanzania (reference
162 NIMR/HQ/R.8z/Vol.IX/3129). Prior to the KIIs and FGDs, a written consent was obtained from each
163 participant. The consent form was written in Kiswahili, the local language, and Each participant was
164 further clarified on the purpose of the study and was ensured of privacy and confidentiality. As part of
165 the consent process, we informed participants they could end the interview at any time or refuse to
166 answer any question. Personal identifiers were removed from all datasets before analyses were
167 undertaken.

168 Results

169 Here we first present the quantitative findings and then the themes identified during the qualitative
170 component of this study.

171 Quantitative findings

172 We estimated current backlog across the six districts to be **5,229** people, over half of which are expected
173 to be found in Bahi and Tandahimba.

174 *Table 4. District level backlog estimates*

Region	District	TT prevalence	Population (15 years and older)	Backlog estimate
Dodoma	Bahi	1.07%	136,599	1,462
Dodoma	Chamwino	0.38%	198,126	753
Lindi	Liwale	0.69%	58,599	404
Lindi	Ruangwa	0.92%	104,729	964
Mtwara	Newala	0.28%	143,004	400
Mtwara	Tandahimba	0.72%	173,056	1,246
Grand total				5,229

175

176 We observed variation between the districts when exploring the timing of each step on the continuum
 177 of care. Bahi and Chamwino have active programs through the year, Liwale and Tandahimba for half the
 178 year, and Ruangwa and Newala for four months out of the year. In Tanzania, dry season is June through
 179 November. Here we see that 59% of cases were identified during dry season in Bahi, 40% in Chamwino,
 180 64% in Liwale, 0% in Ruangwa, 100% in Newala and Tandahimba. Importantly, 53% of treatments
 181 occurred during dry season in Bahi, 39% in Chamwino, 79% in Liwale, 5% in Ruangwa, 100% in Newala
 182 and Tandahimba.

183 The time lag between being identified by a case finder and receiving treatment also varied by district. In
 184 general, the full continuum of care took between 19 and 25 days (Table 5). However, in Liwale it was
 185 much faster (median 5 days and IQR 3-8 days) and in Tandahimba it was much longer (median 97 days
 186 and IQR 92-109 days).

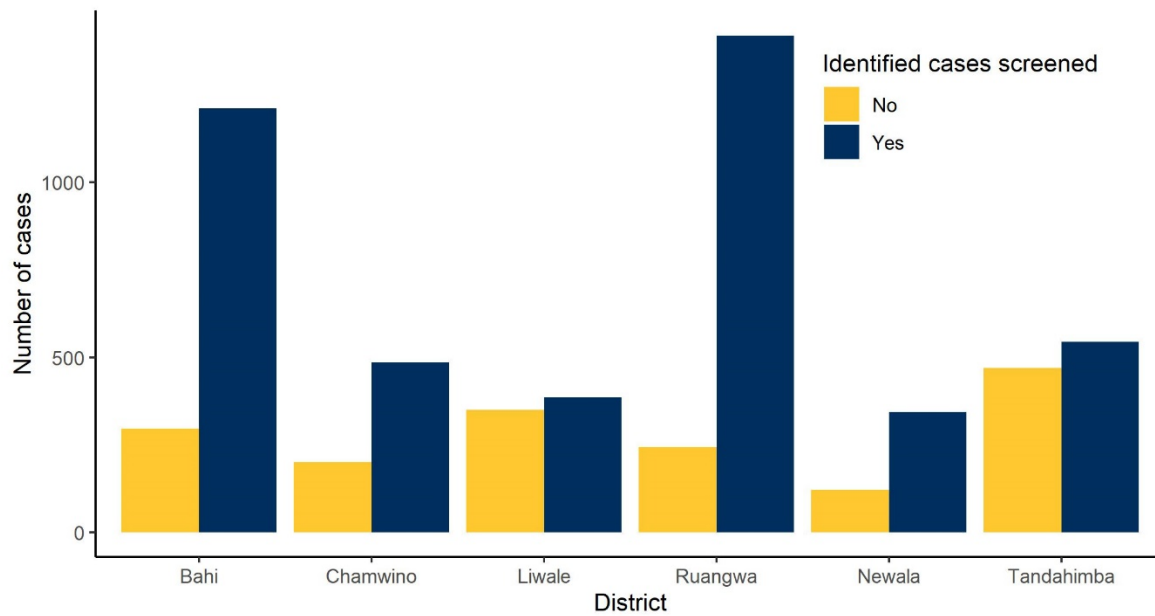
187 *Table 5. Time lag between each step along the continuum of care*

Region	District	Number of days between case identified and screened by eye health professional			Median number of days between case screened by eye health professional and confirmed by surgeon			Median number of days between case confirmed by surgeon and received treatment			Median number of days between case identified and received treatment		
		Median days	IQR days	N	Median days	IQR days	N	Median days	IQR days	N	Median days	IQR days	N
Dodoma	Bahi	24	14-31	1,474	0	0-0	873	0	0-0	866	24	15-31	866
	Chamwino	0	0-0	651	0	0-0	651	19	14-28	438	19	14-28	438
Lindi	Liwale	4	2-8	47	0	0-0	47	0	0-0	43	5	3-8	43
	Ruangwa	22	20-25	310	0	0-0	310	10	4-15	86	25	22-32	86
Mtwara	Newala	25	14-30	90	0	0-0	90	0	0-0	90	25	14-30	90
	Tandahimba	22	13-28	29	0	0-0	29	85	64-87	29	97	92-109	29

188

189 Once identified by case finders, 72% were screened by eye health professionals (ranging from 52% in
 190 Liwale to 85% in Ruangwa) (Figure 1). This means that 28% of the identified cases dropped off the
 191 continuum of care in the second step (Table 6). Of those who were recommended for treatment, 82%
 192 accepted treatment (ranging from 49% in Ruangwa to 96% in Chamwino). Of those who accepted
 193 treatment, all received treatment.

194 *Figure 1. Number of identified cases screened*



195

196 *Table 6. Percent of cases along the continuum of care*

Region	District	Percent of identified cases screened by eye health professional	Percent of screened cases confirmed as positive by eye health professional	Percent of cases confirmed by eye health professional also confirmed by surgeon	Percent of confirmed cases accepted treatment	Percent of accepted treatment cases received treatment
Dodoma	Bahi	79.3%	63.2%	100%	95.5%	100%
	Chamwino	71.6%	71.7%	100%	96.1%	100%
Lindi	Liwale	51.8%	23.8%	100%	88.6%	100%
	Ruangwa	85.2%	30.5%	100%	49.0%	100%
Mtwara	Newala	72.9%	68.2%	100%	86.6%	100%
	Tandahimba	53.8%	75.1%	100%	78.8%	100%
Grand total		71.8%	50.7%	100%	81.7%	100%

197

198 If we assume that those who attended screening are like those who did not, then we could estimate that
 199 across these six districts 1,327 TT positive people were lost before the second step in the continuum of

200 care (Bahi: 270, Chamwino: 187, Liwale: 139, Ruangwa: 116, Newala: 113, and Tandahimba: 501). This
201 means that 25% of the backlog was lost between being identified and screened (Bahi: 19%, Chamwino:
202 25%, Liwale: 34%, Ruangwa: 12%, Newala: 28%, and Tandahimba: 40%). We further estimate that 11%
203 of the backlog was lost between screening and receiving treatment (Bahi: 3%, Chamwino: 3%, Liwale:
204 4%, Ruangwa: 35%, Newala: 10%, and Tandahimba: 10%).

205 We estimate that 689 cases were not identified by case finder, which equates to 13% of the backlog
206 (Bahi: 11%, Chamwino: 13%, Liwale: 29%, Ruangwa: 18%, Newala: 0%, and Tandahimba: 13%). We
207 further explored the dataset in an effort to identify factors that could be contributing to this disconnect.
208 In our regression model, we found no significant association in attending screening and the month the
209 case was identified.

210 The regression model where attending screening is dependent on district and sex, we found that cases
211 identified in Bahi, Ruangwa, and Newala were significantly more likely to attend screenings and that sex
212 was not statistically significant. The regression model where treatment acceptance was dependent on
213 district showed positive people in Bahi were the most likely to accept treatment, followed by Chamwino,
214 Liwale, Newala and Tandahimba. The model showed no significance for Ruangwa.

215 **Qualitative**

216 Interviews were conducted among 119 people with TT across the six districts. 52% of interviewees were
217 female (ranging from 38% to 61% across the districts). The mean (standard deviation) age of interviewed
218 TT positive people who received surgery was 58 years (20 to 85 years old) and those who did not receive
219 surgery was 59 years old (30-90 years old). Of those interviewed, 66% were offered surgery in the
220 summer, 16% in the winter, 14% in the spring and 4% unknown. Of those interviewed, 93% identified
221 themselves as “peasants”, 5% as “not employed”, and 2% “unknown”.

222 Below we present themes identified through the KIIs and FGDs, including feedback of case finding
223 techniques, linkage of identified TT cases to surgeries, and the surgery process. The themes were
224 consistent across districts and so are presented together.

225 Case finding techniques

226 Participants consistently identified similar processes for case finding techniques, which involved house-
227 to-house visits where the individuals in the household were examined using a torch light and identified
228 as having TT or not having TT. If an individual was identified as TT positive, they were provided with
229 information on obtaining surgery. Specific themes expressed in the interviews were: case finding
230 techniques are generally effective; knowledge about TT is a major barrier to case finding; geography is a
231 major barrier for case finding; perceived credibility of case finders is a major barrier for case finding; and
232 motivation of case finders is a challenge.

233 *Error! Reference source not found.*

234 Nearly all who were interviewed expressed the feeling that the current case finding techniques are
235 generally effective. People interviewed who were positive for TT specifically mentioned that they
236 appreciated case finders coming to their home (house-to-house technique) and that this method is the
237 best way to reach the most people.

238 *“Following patients at their home is a very good technique because it will not miss*
239 *patient like me who cannot walk.” – TT positive person in Tandahimba*

240 Case finders agreed that the house-to-house technique is an effective approach.

241 *“The process is excellent, because we visit every house; this process assures that no*
242 *one is left behind. If we were to invite them somewhere at central point for*
243 *examination, due to various reasons some will not come.” – Case finder in Bahi*

244 *knowledge about TT is a major barrier to case finding*

245 Most TT positive people interviewed were not aware of TT prior to being diagnosed, Though a few did
246 mention hearing about TT on the radio or from other community member. The district-level health
247 officers thought that this lack of knowledge may contribute to misconceptions about the program and
248 fear of case finders.

249 *“One of the barriers is poor understanding and awareness of the importance of TT*
250 *surgery. When TT case finders visit the household, some people run away to avoid*
251 *examination and identification.” – District-level health officer in Chamwino*

252 *geography is a major barrier for case finding*

253 The majority of those interviewed specifically mentioned that traveling far distances to remote villages
254 is difficult for case finders and that these populations may be missed during case finding.

255 *“The first challenge is the distance between households. Some are very far for the*
256 *case finder to visit. The second challenge is lack of transport; the case finders have to*
257 *walk from one house to the other.” – District-level health officer in Ruangwa*

258 *“A challenge is geographical, in some communities people live far apart, we are*
259 *forced to walk long distances to reach them and often we can’t make it. This is*
260 *because we don’t have means of transport.” – Case finder in Liwale*

261 *perceived credibility of case finders is a major barrier for case finding*

262 Some TT positive people and surgeons interviewed mentioned that community members are
263 uncomfortable with the case finders providing advice on eye health because they know the case finders
264 and are not aware that they have been trained. Other TT positive persons interviewed mentioned that

265 they felt more comfortable with the case finders because they are from their community and know and
266 trust them. Case finders also spoke about this conflicting situation.

267 *“Poor understanding of the case finder’s role by the community makes it difficult for*
268 *some people to agree to an eye examination. They know and believe that a case*
269 *finder is not an eye professional and even some who accept examination disagree*
270 *with the examination findings.” – TT surgeon in Bahi*

271 *“The main challenge is for the community to accept the TT case finders eye*
272 *examination. They believe case finders are not eyecare professionals.” – TT surgeon*
273 *in Chamwino*

274 *and motivation of case finders is a challenge*

275 District-level health officers and case finders noted that motivation of the case finders can be a
276 challenge. In some districts the case finders are only paid for the positive cases they identify. Case
277 finders also have other responsibilities and may find it difficult to prioritize case finding if they are not
278 compensated in a fair way.

279 *“Case finders also have their income generating activities, so if these two*
280 *responsibilities are to be done at the same time the likelihood of the case finder to*
281 *priorities his personal duties is high as he has to work in order to earn money.” –*
282 *District-level health officer in Ruangwa*

283 *“We case finders work as volunteers, but the task is too tough. As per now there is a*
284 *very big variation when it comes to the issue of incentives to case finders. This kind of*
285 *situation demoralizes us.” – Case finder in Newala*

286 Linking identified TT cases to services

287 Participants consistently identified similar processes when describing the steps, they took to receive

288 surgery. It was often described that screening by eye health professionals, confirmation by surgeon and

289 treatment happens on the same day.

290 *“First, the case finder visited me at home. He examined me and identify that I have*
291 *TT. He gave me the date when the TT surgery team would come to serve us. On the*
292 *day of surgery, I was brought here by a case finder. They examine me again and*
293 *confirmed that I have TT. I went on to receive the TT operation.” – TT positive person*
294 *in Bahi*

295 Specific themes expressed in the interviews were all related to barriers linking people to services. The

296 barriers identified were: fear and misconceptions; geographical distance; rainy season; insufficient time;

297 lack of information on assistance accompanying TT surgery; and sex of TT patient.

298 *fear and misconceptions*

299 Fear was the most common barrier to obtaining surgery mentioned by all groups. It is commonly

300 thought that TT surgery causes blindness.

301 *“In some places you will find the rumors that it [TT surgery] is a blinding procedure, or*
302 *very traumatic, and in other communities that the surgery is meant to destroy eyes.”*
303 *– TT surgeon in Bahi*

304 *geographical distance*

305 Distance from the surgical site was also noted as a barrier among a variety of persons interviewed.

306 *“There are some communities that live very far or in the areas where they can’t*
307 *access health services during rainy season. Particularly those who live on the other*
308 *side of the river; they cannot cross to this side.” – Case finder in Ruangwa*

309 *“It is a very long distance from where I live to the service site. If you do not have*
310 *means of transport you must walk; no one can afford to do that.” – TT positive person*
311 *in Liwale*

312 *“The difference is on the patient’s side, some need transport to reach the camp and*
313 *yet they cannot afford it, so they decide to walk. These will always reach the camp*
314 *very late.” – Case finder in Tandahimba*

315 *rainy season*

316 Offering surgery during rainy season may disenfranchise many people to obtain surgery. This barrier was
317 particularly prevalent in Ruangwa.

318 *“I did not receive surgery because it was a rainy season and I was busy with*
319 *agricultural activities.” – TT positive person in Ruangwa*

320 *“During rainy season people are very busy with agricultural activities. People will not*
321 *accept surgery because they believe after receiving surgery, they will have to spend a*
322 *number of days without working and therefore may not be able to attend their*
323 *agricultural duties.” – District-level health officer in Ruangwa*

324 *“When I was supposed to go for surgery it was a high time for agricultural activities,*
325 *so I did not go because of that.” – TT positive person in Bahi*

326 *“Many people do not receive information on availability of service, and during rainy*
327 *season most people move to their farms so case finders can’t find them at their*
328 *homes.” – TT positive person in Newala*

329 *“I request the TT surgery to be offered from November onwards.” – TT positive person*
330 *in Tandahimba*

331 *geographical distance; rainy season; insufficient time*

332 A common barrier mentioned was short duration of surgical camps and the lack of timely
333 announcements about surgical camps.

334 *“I did not receive surgery because when I was ready for surgery the doctors had*
335 *already left, so I had nowhere to get it.” – TT positive person in Chamwino*

336 *“The duration of service provision should be increased from one day to two or three*
337 *days, without doing that we will continue making mistake by missing people.” – TT*
338 *positive person in Newala*

339 *“I waited for surgery all day without receiving it. On second day, I again waited all*
340 *day without receiving surgery. When they came later for another camp, I was not in*
341 *the village.” – TT positive person in Tandahimba*

342 *“We should increase the frequency of conducting TT surgery camps. The interval*
343 *needs to be small for the good of the program as well as patients whom may be lost*
344 *if it takes too long to wait for the service.” – Case finder in Tandahimba*

345 *ack of information on assistance accompanying TT surgery*

346 TT positive persons interviewed were not aware of any post-operative assistance until they arrived for
347 surgery. The need for assistance is a barrier to seeking care, and participants suggested that providing

348 information on assistance may have encouraged some of those interviewed who did not receive surgery
349 to receive it.

350 *“They did not mention any assistance to be provided to me.” – TT positive person in*
351 *Bahi (refused surgery)*

352 *“I was not informed about any form of assistance.” – TT positive person in Chamwino*
353 *(refused surgery)*

354 *“No assistance was offered. I needed food and transport fare to go to the hospital.” –*
355 *TT positive person in Tandahimba (refused surgery)*

356 *ex of TT patient*

357 In these communities it is common for men to be decision-makers, so women may have an additional
358 barrier of convincing their husband to allow them to seek surgery.

359 *“Men in our community are decision makers so when they are afraid of surgery, they*
360 *will find a way to make a wife not receive surgery.” – TT positive person in Bahi*
361 *(male)*

362 *“When the sick person is a wife; the husband may refuse on her behalf.” – Case finder*
363 *in Liwale*

364 *“For women who are married, a husband decides whether his wife can go for surgery*
365 *or not. Particularly during rainy season most men will not allow their wife to go for*
366 *surgery, they will need them to work together in the farm.” – TT positive person in*
367 *Ruangwa (female)*

368 Surgery process

369 Participants consistently identified similar processes for receiving surgery which involved traveling to the
370 surgical site, being re-examined, provided surgery and then being escorted home.

371 *“They queued us for examination one after the other. They told me one eye has TT,*
372 *and some of my colleague had both eyes having TT. After that we queued again for*
373 *surgery where they were calling one by one to the operating room. After surgery I*
374 *was transported back home.” – TT positive person in Chamwino*

375 Specific themes expressed in the interviews were: persons with TT who received surgery were generally
376 pleased with the outcome; conflicting opinions on assistance after surgery; and inconsistent assistance
377 was provided after surgery.

378 *ersons with TT who received surgery were generally pleased with the outcome*

379 The majority of those interviewed specifically mentioned positive outcomes from their surgery.

380 *“I had severe photophobia after I was identified I got treated and now am fine.” – TT*
381 *positive person in Liwale*

382 *“It has helped me to gain my good healthy eyes; no more pain, tearing, difficult in*
383 *reading letters or even newspapers. Now I have no problem.” – TT positive person in*
384 *Bahi*

385 *“Am now fine I can do all my duties comfortably.” – TT positive person in*
386 *Tandahimba*

387 *conflicting opinions on assistance after surgery*

388 There was inconsistent messaging on whether the assistance provided after surgery was sufficient.

389 Some TT positive persons interviewed expressed appreciation for the assistance provided and felt that it
390 was enough.

391 *“It is a good assistance and is enough even for other patients.” – TT positive person in*
392 *Bahi*

393 While others had different experiences and circumstances at home. Participants mentioned many
394 instances where additional assistance is needed, such as patients who live alone or who are the
395 caregivers to others.

396 *“If you live alone or you have small kids to take care of and you agree to receive*
397 *surgery; they will cover your eyes and you cannot do anything. There will be no one to*
398 *serve my kids, so do you want my kids to die of hunger because of this surgery? – TT*
399 *positive person in Ruangwa (declined surgery)*

400 *“I will not be able to work and so will have no income for some days; and considering*
401 *that I live alone this is a challenge. Who will take care of me at home after surgery?*
402 *Because I know after surgery we are not allowed to cook in a smoky kitchen and*
403 *sometimes both of your eyes are covered. You can’t do anything without support.– TT*
404 *positive person in Ruangwa (declined surgery)*

405 *“TT persons taking care of others at home will not accept surgery. I know some TT*
406 *persons who have not received surgery because of this but they show obvious need of*
407 *surgery.” – Case finder in Bahi*

408 *“Additional assistance is needed to support those who are independent and live*
409 *alone. After surgery they cannot do anything for few days therefore, they need*
410 *financial assistance to run their daily life at home.” – Case finder in Bahi*

411 *“There is an economic barrier where people who receive surgery struggle to survive*
412 *for those few days postoperatively when they are not allowed to work. This makes*
413 *some people decline surgery trying to avoid this challenge.” – TT positive person in*
414 *Newala*

415 *inconsistent assistance was provided after surgery*

416 Many TT positive persons interviewed mentioned receiving; transportation, medicine and food after
417 surgery. This was most common in Dodoma region. However, many others did not receive these
418 assistances (particularly in Lindi region and Newala district).

419 *“I received transportation back home after surgery and food at campsite. Medicines,*
420 *postoperative care on day one for bandage removal and more medicine after*
421 *bandage removal – TT positive person in Chamwino*

422 *“No assistance was offered; I just went back home.” – TT positive person in Ruangwa*

423 *“I only got medicine after surgery, but to go home I had to find somebody on my own*
424 *to escort me back home. After I received surgery there was nothing, not even drinking*
425 *water.” – TT positive person in Liwale*

426 *“No assistance was offered to me. Even the medicine I bought myself. They said they*
427 *were supposed to give medicine for free, but they forgot to come with it.” – TT*
428 *positive person in Newala*

429 Discussion

430 Linking TT positive people to TT surgery is essential for reaching the trachoma elimination targets [4].

431 Our findings suggest that a large portion of TT positive people are not being identified by case finders,

432 and those who are identified are not sufficiently attending screenings and progressing along the

433 continuum of care to receive surgery. Of those who do receive surgery, our findings show self-reported

434 improvement in vision, relief of pain and general positive perceptions of their outcome. This is

435 consistent with a previous study in Tanzania, which found high TT surgical success rates [23].

436 Our qualitative findings suggest that the current house-to-house case finding technique is an effective

437 approach in identifying TT positive people. However, the program data illustrates that an estimated 13%

438 of cases were not identified by case finders. Many factors are likely contributing to case finders not

439 identifying these people. Most participants who had TT were unaware of TT prior to being diagnosed.

440 This lack of education about TT, availability of surgery, and what the surgery entails may contribute to

441 refusal of examination and therefore not entering the continuum of care at all. Additionally, people who

442 live in remote locations may not be reached by case finders. Case finders are generally unpaid and do

443 not have access to transportation, which means that they may lack the motivation and ability to reach

444 these far away populations. An important challenge case finders face is credibility within their

445 communities. Some people are uncomfortable with case finders providing advice on eye health and so

446 decline to be examined. Finally, the program data shows that in some districts case finding activities

447 take place during rainy season. This is agricultural season in Tanzania when people with agricultural

448 responsibilities are likely to be away from their homes and so will not have an opportunity to be

449 identified.

450 Once identified, the largest gap in the continuum of care is between being identified and screened.

451 Screening by eye health professions, confirmation by surgeons, and receipt of surgery often happen on

452 the same day. This means that when people arrange to go in for screening, they also are expecting to
453 receive surgery. Our qualitative findings provide many barriers for screening attendance and
454 subsequently surgical uptake. The time lag between identification and screening may play a role in
455 attendance. People were significantly more likely to attend screenings in Bahi, Ruangwa, and Newala
456 districts. On average, these three districts allowed nearly three weeks for an identified person to
457 prepare themselves to attend screening. The median number of days between identification and
458 screening was 24 in Bahi (interquartile range (IQR): 14-31), 22 in Ruangwa (IQR: 20-25) and 25 in Newala
459 (IQR: 14-30). This aligns with our qualitative findings where interviewees mentioned needing more time
460 to plan travel to receive surgery and arrange for help after surgery.

461 After surgery, patient's eyes are covered with a dressing, and this dressing stays in place until the next
462 day. This impedes vision and requires that someone assist the patient at home. Patients are also advised
463 to stay away from cooking fires for the first few days after surgery. Patients who live alone or who are
464 the caregivers to others many require a provision of food for several days after surgery. This finding is
465 consistent with past studies where requiring help after surgery was found to be a barrier for obtaining
466 surgery [24, 25]. As with identifying cases, lack of knowledge and misconceptions lead to fear of surgery
467 and in turn lack of screening attendance. Additional studies have consistently found misconceptions and
468 fear to be barriers to surgical uptake [25-27]. Logistics certainly play a role in attendance. People who
469 have agricultural responsibilities may not be able to attend during rainy season or people who live in
470 remote communities may not be able to travel to the surgical site. Communities that live far from
471 central sites often do not receive information about the surgical camps until it is too late.

472 Engaging with community leaders to share information about TT with their communities and enlisting
473 people who have already received surgery to witness in their communities may encourage consent of
474 examination by case finders and increase surgical uptake. A previous study in Tanzania found village
475 based promotion efforts [28] and witnessing others who had received surgery [29] improved surgical

476 uptake. Other programs could be avenues for providing information on TT. Lymphatic Filariasis Mass
477 Drug Administration campaigns, mosquito net distributions and family planning activities were all
478 mentioned as opportunities to sensitize and distribute information on TT. Finally, providing support to
479 case finders could improve motivation and reach of the activities.

480

481

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