Longitudinal Study of Trachomatous Trichiasis in The Gambia: Barriers to Acceptance of Surgery

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Purpose. Investigation of compliance with surgery for trachomatous trichiasis has become a priority of the World Health Organization. This study was conducted to investigate attitudes toward trichiasis and its treatment and to determine the rate of surgical uptake in The Gambia.

Methods. A 1-year longitudinal study was performed in 190 subjects with trichiasis. Persons with major trichiasis (involving five lashes or more) were referred for surgery, and those with minor trichiasis were advised to epilate. Outcome measures included attitudes toward trichiasis and its treatment, reported barriers to surgical uptake, acceptance rates for surgery, and factors affecting acceptance.

Results. Twenty-three percent (95% confidence interval [CI] 16.5%–30.6%) of subjects with major trichiasis attended for surgery during the year. Degree of ignorance about surgery, symptoms impeding work, and a multiple income source for the head of household predicted attendance. Reported lack of time predicted nonattendance. Sixty-eight percent of patients who had undergone surgery were trichiasis free at last follow-up.

Conclusions. Poor attendance for surgery remains a problem in The Gambia. Barriers include ignorance and lack of time and money. Health education and surgical delivery strategies are needed to overcome these barriers. Regular audit of surgical results is necessary, with retraining where indicated. (*Invest Ophthalmol Vis Sci.* 2002;43:936–940)

Trachoma, a chronic conjunctivitis caused by *Chlamydia trachomatis*, has sight-threatening complications, such as trichiasis and corneal scarring. It remains the world's commonest form of preventable blindness,[1] mainly affecting disadvantaged communities. The World Health Organization (WHO) estimates that 146 million children and adults have active inflammatory trachoma, and that 10 million people have trichiasis and urgently need surgery.[1]

WHO is promoting the Global Elimination of Trachoma as a public health problem by the year 2020 (GET 2020) and has adopted the SAFE strategy—surgery for entropion and trichiasis, antibiotic treatment for active infection, and the promotion of both facial cleanliness and environmental improvement to reduce transmission—to achieve this goal.[2] Surgery is the one component of the SAFE strategy that has been shown to prevent blindness.[3] It usually produces immediate and dramatic relief of discomfort and in some subjects an improvement in visual acuity. For these reasons, surgery is usually the first component of the SAFE strategy to be introduced into a community and is important in gaining community support for the other elements of SAFE, which may not be perceived to have these immediate and obvious benefits. In practice, however, acceptance of surgery in affected communities has been disappointingly low.[4,5] The need to investigate barriers to and improve uptake of trichiasis surgery was identified as a research priority by the WHO Alliance.[6]

For the past 10 years, The Gambian National Eye Care Program has routinely provided trichiasis surgery, predominantly performed by trained ophthalmic nurses, at a number of rural health centers in addition to the two main hospitals. There is a charge of $2.50 US per eye. The standard surgical technique used in The Gambia is the tarsal rotation procedure reported by Bog et al.[7] to be safe and effective when performed by a trained nurse in the community. It is similar but not identical with bilamellar tarsal rotation, which was found to be the best procedure among those tested in a randomized controlled trial.[3] Current Gambian practice is to refer only patients with major trichiasis (five or more lashes abrading the globe) for surgery and to treat minor trichiasis with repeated epilation.

Compared with other communities affected by trachoma, access to surgery in The Gambia is good, but surveys continue to indicate that uptake is low. There are very few data on cultural attitudes toward trichiasis and its treatment, which may underlie this poor uptake. We conducted a cohort study to assess surgical uptake and the factors influencing it under practical operational conditions in The Gambia. Progression of disease in attenders and nonattenders for surgery was also investigated and the findings presented in a separate article.

Methods

Ethical Approval

The study was designed in accordance with the Declaration of Helsinki and approved by the joint Gambia Government/Medical Research Council Ethics Committee.

Recruitment

Three geographic divisions of The Gambia with the highest prevalence of trachoma in a 1996 national survey[8]—Western Division, North Bank Division, and Lower River Division—were chosen for village-based recruitment of patients with trichiasis who had not been surgically treated. Villages of varying size and ethnicity were chosen. The importance of lid surgery and the nature and purposes of the study were explained to village leaders during sensitization visits. The village leader then publicized the study (through messengers and mosque loudspeakers), inviting subjects with past or present problems with lashes rubbing on the eye to attend a central point in the village.

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Further community screening was not conducted. Persons with trichiasis or signs of epilation were eligible for recruitment, unless they had already had lid surgery, and gave individual consent after further explanation in an appropriate local language. All persons were offered immediate epilation and a tube of tetracycline ointment to apply twice daily. Those with minor trichiasis were treated by epilation, and those with major trichiasis were referred for surgery, according to usual Gambian practice. Explanation of the nature of the surgery was given to patients needing it, emphasizing that it could be performed as day surgery and that 1 week was the maximum time necessary off work after surgery.

Questionnaire Preparation and Testing

A questionnaire surveying demographic and socioeconomic information, cultural attitudes toward trichiasis, and previous exposure to eye care was administered to all patients. A second questionnaire about attitudes and barriers to lid surgery was administered to patients who needed surgery. Questionnaires were administered by Gambian eye care staff in an appropriate local language. The questionnaires were devised with reference to previously published literature on cultural attitudes, health-care–seeking behavior, and barriers to eye surgery; ongoing qualitative investigation (focus groups and semistructured in depth interviews) of community concepts of trachoma and its treatment; and informal interviews with "key informant" staff members of the National Eye Care Program. Barriers to acceptance of surgery were classified as primary or secondary, according to whether they were volunteered as unprompted answers to open questions or as prompted answers to closed questions, respectively, and were pooled over three interviews at baseline and follow-up. Sample interviews were taped and the transcripts back translated into English for validation.

Clinical Examination

Clinical examination was performed by an ophthalmologist (RJCB). Trichiasis in an eye was classified as major trichiasis if five or more lashes were abrading the globe and as minor if four lashes or fewer were abrading the globe. Subjects were classified according to their worse eye. In patients in whom lashes had been epilated, the classification of major or minor trichiasis was based on the extent of epilation estimated by the number of bare lash follicles present. Visual acuity was measured in daylight with a standard tumbling-E Snellen chart. The standard WHO definitions of visual impairment (visual acuity worse than 6/18 in the better eye) and blindness (visual acuity worse than 3/60 in the better eye) were used.

Follow-up

Examination and questionnaire administration were repeated at 6 and 12 months. All patients with major trichiasis were referred for surgery at each visit.

Data Handling and Analysis

Data were analyzed on computer (Epi-Info software, ver. 6; USD, Snellville, GA). The χ^2 test was used to test significance of pair-wise associations. Multiple logistic regression was used to model determinants of surgical attendance on computer (Logistic software). A number of possible predictors of attendance or nonattendance including sex, age, geographic location, demographic and socioeconomic indicators, severity of disease, visual status, and reported barriers to surgery were tested for influence on attendance.

Results

Study Subjects

Table 1 provides a profile of subjects in the study. Patients with major trichiasis (mean age, 55 ± 14 years [SD]) were older (t = 3.4, $P < 0.001$) than those with minor trichiasis (mean age, 47 ± 16 years). Seventy-five percent of female subjects reported a source of cash income, most commonly from garden produce or rice farming. Ninety-six percent of male subjects-husbands of female subjects reported a source of cash income usually from groundnut farming or businesses. Ten percent of female subjects and 6% of male subjects-husbands reported multiple income sources. The families of 45% of all subjects owned livestock. Of 171 subjects tested at baseline 93 (54%) had normal visual acuity, 65 (38%) had visual impairment, and 13 (7%) were blind.

Table 1. Profile of Study Subjects

	Major Trichiasis	Minor Trichiasis
Female	100 (74)	44 (80)
Western Division	69 (51)	36 (65)
Gambian citizens	122 (91)	53 (96)
Mandinka ethnic group*	109 (81)	32 (58)
Muslim religion	131 (97)	49 (89)
Attended Koranic school	30 (22)	9 (16)
Attended Western school	4 (3)	5 (9)
Bilateral trichiasis*	119 (88)	25 (45)

Total in study, 190; patients with major trichiasis, 135; patients with minor trichiasis, 55. Data are number of patients, with percentage of the subgroup in parentheses.

* Significant difference in proportion ($P < 0.05$).

† 84 bilateral major; 35 minor in fellow eye.

Access to Eye Care Services

One hundred and thirty-six (73%) of 190 patients had previously had their eyes examined by a health worker. Of the 135 patients with major trichiasis, 102 (75%) had undergone previous eye examination and 48 (36%) had been advised to have surgery. Of these, 36 (75%) knew the location of the nearest surgical center, 11 (23%) knew the cost of surgery, and 9 (19%) knew that admission was not required for the surgery. The mean estimated journey time (one way) from the patients' homes to the nearest surgical center was 42 minutes (n = 190; range; 2–240 ± 38). The mean cost of the journey (return) was 7 Dalasis (10 Dalasis = $1 US; n = 190; range, 0–40 ± 7).

Patients' Perceptions of Trichiasis and Treatment Practices

Subjects' reported perceptions of the duration and nature of their symptoms and of the causes and consequences of trichiasis and its treatment are summarized in Table 2. Details of who performs epilation and what tools and techniques were used are also given.

Barriers to Surgery

Barriers reported by patients as having prevented them from previously attending for surgery are listed in Table 3. Being too busy to take time out for surgery was reported more frequently ($\chi^2 = 9.12$, $df = 2$, $P = 0.01$) among patients aged between 40 and 60 years (32/54; 59%) than among younger patients (2/11; 18%) and older patients (19/52; 36%).

Attendance for Surgery

All 135 patients with major trichiasis were referred for surgery at baseline, and all nonattenders plus a further 13 (in whom disease had progressed from minor to major) at 6 months. Of the 148 subjects thus referred, a total of 34 patients attended for surgery (attendance rate, 23%; 95% confidence interval [CI] 16.5%0–30.6%) in the 12-month period. Significant predictors of attendance or nonattendance in a multiple logistic regression model are listed in Table 4. There were no significant

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TABLE 2. Perceptions of Trichiasis, Treatment, and Surgery

Perception	Frequency (%)*
A. Perceptions of Trichiasis and Treatment Practices with Epilation	
Used local word for trichiasis	149 (78)
Symptoms	
For more than 10 years	51 (27)
For 5–10 years	38 (20)
Ocular pain	168 (88)
Epiphora	97 (51)
Visual impairment	88 (46)
Interferes with work	90 (48)
Cause	
Unknown	89 (47)
By Allah	42 (22)
By infection	18 (9)
Consequences	
Would deteriorate if untreated	61 (32)
Leads to visual impairment	44 (23)
Treatment with epilation	
Epilate	161 (85)
Weekly or more frequently	68 (36)
By	
Self	54 (28)
Friend or family member	98 (52)
Health worker	9 (5)
Using	
Locally made forceps	89 (47)
Fingers	54 (28)
Sharp blade	7 (4)
Hot ash as adjunct	42 (22)
Other treatments	
Traditional eye medicine (usually a soaked-leaf preparation)	40 (21)
Western medicine (usually ointment)	109 (58)
Perception	**Frequency (%)†**
B. Perceptions and Experiences of Surgical Patients	
Would recommend to others	32 (94)
Pleased with result	29 (85)
Worth expenditure	27 (79)
Already recommended to others	11 (32)
Benefits of surgery	
Eyes more comfortable	20 (59)
Improved vision	6 (17)
Convenience of not epilating	4 (12)
Outcome	
Not epilating since surgery	21 (62)
Work easier since surgery	18/28 (64)
Vision improved since surgery	27 (79)
Vision worse since surgery	3 (9)
Process	
Surgery was pain free	21 (62)
Pain during operation	8 (23)
Pain after operation	4 (12)
Time off work	
1 week	6 (18)
Up to 3 months	17 (50)
6 months or more	4 (12)
Cost	
Paid standard charge	25 (73)
Paid more than standard charge	4 (12)
Free	5 (15)
Follow-up	
Seen for review 1 week after surgery	34 (100)
Second follow-up at 2–3 weeks	10 (29)

* $n = 190$.
† $n = 34$, unless otherwise stated.

TABLE 3. Barriers to Surgical Uptake Reported by Patients Requiring Surgery

Reported Barrier	Primary (%)	Secondary (%)
Symptoms not bad enough	14 (10)	43 (32)
Previous bad experience with surgery	7 (5)	28 (21)
Fear	34 (25)	57 (42)
Epilation was a good enough treatment	4 (3)	58 (43)
Traditional eye medicine better	4 (3)	18 (13)
Family opposition	4 (3)	18 (13)
Too expensive	80 (59)	101 (75)
Patient too busy	39 (29)	60 (44)
No escort available	2 (2)	27 (20)
Did not know about or how to get surgery	19 (14)	28 (21)
Other	66 (49)	

Primary barriers were those offered by the patient in response to the open question, "Why have you not been for surgery?" Secondary barriers were those identified when the patient answered yes in response to a closed question, "Was surgery too expensive?" for example. Primary barriers classified as other included having traveled when the surgery was available, a relative whose permission was required having traveled, and patient's indecision or procrastination. $n = 135$. Data are frequency of reported barrier, with percentage of group needing surgery in parentheses.

differences between male and female attendance rates or predictors of attendance between males and females. Baseline visual status did not influence surgical attendance.

Follow-up

One hundred seventy-three (91%) of 190 subjects were seen at 6 months and 169 (89%) of 190 at 12 months (159 at both 6 and 12 months, 14 at 6 but not at 12 months, 10 at 12 but not at 6 months, and 7 at neither time point). Therefore 183 (96%) subjects were seen at either 6 or 12 months. Eight (4%) subjects died during the 12 months (three in the first 6 months and five in the second after having been visited at 6 months), and two refused to be reinterviewed or examined at a follow-up visit. The remainder of those lost to follow-up had moved to an unknown location. Ten patients who had moved within The Gambia were successfully traced.

Results of Surgery

At the last available follow-up 11 (32%) of 34 subjects had experienced recurrent trichiasis. The perceptions of the 34 patients who underwent surgery are given in Table 2B. Results of surgery, complications, and progression of disease in attenders and nonattenders are presented in a separate article.

TABLE 4. Factors Affecting Attendance for Surgery in a Multiple Logistic Regression Model

Factor	All Patients (Odds Ratio [95% CI])	*P*
Predict attendance		
Multiple male income source	22.03 (1.24–392.99)	0.017
Symptoms interfering with work	6.79 (1.69–27.29)	0.003
High journey cost	8.33 (1.56–50.00)	0.010
Previous ignorance of surgery	25.70 (5.90–111.97)	0.000
Predict nonattendance		
Geographic district	4.76 (1.30–16.67)	0.017
Heard radio broadcast	7.61 (1.23–46.98)	0.015
Too busy	15.31 (2.96–79.36)	0.000

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Discussion

We found that uptake of eyelid surgery for trichiasis treatment in The Gambia was disappointingly low at 23%. Together with similar figures of 18%[9] (2-year follow-up) and 27%[4] (9-year follow-up) reported in Tanzanian women and 35% in Malawian women (9–12-month follow-up),[5] this indicates a widespread problem that needs careful investigation. All patients requiring surgery were given careful counseling and referral at enrollment, but attendance remained low. Most patients had had eye examinations, but only a third of subjects who needed surgery reported having received prior advice to this effect. There may have been underreporting of this prior advice because subjects were being questioned about nonattendance. Furthermore, recalcitrant nonattenders could have been overrepresented by the sampling method, leading to an underestimate of the uptake rate that would be expected in a naïve population. Against this, however, those with the greatest fear of Western medicine or surgery may have decided not to appear for recruitment at all. A randomly selected population-based sample might have provided more accurate data but would have been difficult because of time and logistic constraints and the need for repeated visits. Furthermore, even if random sampling were attempted, even use of this method can be confounded by subjects who are not interested in participating. The case-finding technique used resulted in most patients coming from the Western Division and hence an overrepresentation of Mandinkas who predominate in that region. Mandinkas comprise approximately 40% of the national population but 75% of the study sample and were also overrepresented in cases of major compared with minor trichiasis. The effect of this on the results is uncertain. Ethnicity is not an obvious marker for geography or socioeconomic status in The Gambia, although cultural practices vary. The Mandinkas are the largest ethnic group in The Gambia and, although prevalent in the Western Division, are scattered throughout the country.

Another possible source of bias in the attendance results is the classification into minor and major cases. It is likely that mild cases of major trichiasis were mistakenly classified as minor (because of epilation) more often than the reverse (minor trichiasis cases being classified as major). This would have the effect of biasing the sample referred for surgery toward the more severe end of the spectrum, tending to increase attendance rates.

Most subjects recruited had traditional agricultural lifestyles and little formal education, which is typical of rural Gambians. The subjects tended to regard trichiasis as painful and visually impairing but not as a long-term threat to vision (Table 2). The majority opted for epilation, preferring it to traditional medicine, which suggests that there is a degree of acceptance that the problem and solution are mechanical. Some subjects could have underreported their more traditional beliefs to an investigating team they identified with Western medicine, but the cultural attitudes toward trichiasis found in this study did not seem inimical to the concept of lid surgery.

Attendance for surgery was higher than average in two geographic districts. In the districts with highest uptake, surgery is performed at a well-established mission hospital. Variation in attendance may reflect the quality of relationship between the population and the local community health workers and perceptions of the work of the surgical centers. This geographical variation in attendance limits the generalizability of the study—a randomly selected sample would have overcome this but was not feasible, for the reasons given earlier. Patients who reported not knowing how to get surgery as a barrier to previous attendance were more likely to attend for surgery. This was the only barrier to attendance reduced by enrollment in the study, and thus this finding was expected and tends to support the validity of at least part of the questionnaire process. It suggests that there are patients who do not have surgery, simply because they have not heard about it and how to get it. These patients were more likely to be of minority (non-Mandinka) ethnic origin, suggesting that such groups may require specific targeting. The problem of not knowing how to get surgery despite a community program has also been reported in Tanzania where nonacceptors reported not knowing that surgery was available in their villages.[4]

Most subjects reported hearing the National Eye Care Program's radio broadcasts, but it is disappointing that this predicted nonattendance for surgery. The content of such broadcasts deserves examination. Radio broadcasts have been used occasionally to advertise traveling eye camps, and it is possible that patients may be confused, waiting for the surgery to come to them. Being "too busy" was the only reported barrier that predicted nonattendance. This was more common among those aged between 40 and 60 years, who bear much of the responsibility for both agricultural and domestic work. The importance of work was illustrated by increased attendance for surgery by those whose symptoms were interfering with work. Most patients reported taking more time off work than is necessary after eyelid surgery. Despite the advice given at referral, the subjects or other patients who advised them may have confused lid surgery with cataract surgery, for which advice to take 3 months off work after surgery would be usual. Given the importance attached to work by the subjects, the program should address this misconception during staff training and in health education.

Cost of surgery was most frequently reported as a barrier, albeit one that did not correlate with attendance. A typical patient with bilateral trichiasis had to pay approximately $6 US for the journey and surgical fee together (allowing two return journeys, one for surgery and one for follow-up). Data are not available throughout the areas studied, but it has been estimated in a rural area of the North Bank Division that 45% of adults have an income of less than $150 US a year. More than half the patients may have reduced this annual total by at least a quarter by taking 3 months or more off work after surgery. There may be additional indirect costs: The patient may travel to the health center with a friend or relative who also loses a day's work and may require assistance with childcare, which again may deprive someone else from engaging in work. Men and wives of men with multiple income sources were more likely to attend for surgery. These men typically had a nonagricultural occupation, such as trading or construction, in addition to farming and probably therefore had a more stable income, because farming income tends to be seasonal.

Alternative cost recovery strategies should be considered to reduce the cost to patients. Alternative strategies could include a means-based fee system[10] or preserving a surgical fee but providing free transport, or eliminating the health center costs and fees by providing surgery in the patients' villages. A separate study of surgical compliance in The Gambia compared attendance for free surgery in health centers (44%) with free surgery in subjects' villages (66%).[11] Although the studies are not directly comparable, the figures suggest that attendance might be higher if the surgical fees were waived. It should be noted, however, that surgical acceptance among Tanzanian women was low, even with the provision of free lid surgery.[4] It is important to state why surgical fees were not waived during the 1-year period of this longitudinal study. The purpose of the study was to investigate surgical uptake under the existing National Eye Care Program provision. The Gambian health service, like many other developing countries has to rely on an element of cost recovery, and the effect of this on uptake of services is not clear. To have waived the surgical fees at enrollment into this study may have benefited those who were

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fortunate enough to be recruited but would not have yielded information about the true situation in The Gambia or many other developing countries. In contrast, this study was conducted under practical operational conditions and will therefore provide valuable information to program planners about how the service and cost recovery may be modified. All subjects were offered free surgery with free transport at the end of the study.

Geographic access to surgery has been reported as an obstacle in Tanzania[9] but does not seem to have been a major barrier to surgical uptake among these subjects in The Gambia. Most patients knew where the nearest surgical center was and could get there in less than 1 hour. It is hard to explain why more expensive journeys were predictive of attendance, but this suggests that journey cost is not an important barrier.

The results of surgery are likely to affect attendance rates. Although 80% of surgical patients reported themselves pleased with the results and the surgery worth the expenditure, only 68% were trichiasis free after, at most, 1 year. This is worse than comparable reports of 77% success at 21 months[3] and 81% at 24 months.[7] Early recurrence is likely to be related to surgical technique. Community surgery programs entail larger numbers of surgeons being trained and possible faster progression toward unsupervised surgery. It is important that structured training programs be adhered to, accurate surgical records kept, and follow-up performed to allow audit and retraining when necessary. Twenty-three percent of surgical patients experienced intraoperative pain and 12% postoperative pain, which is of concern, particularly in the context of low uptake. Training in local anesthetic technique must be part of all surgeons' training, and issuance of simple postoperative analgesia might be helpful.

Although a number of factors emerged as important in predicting attendance or nonattendance for surgery, the large confidence intervals (Table 4) for the odds ratios in the regression model illustrate the difficulties of trying to quantify their significance. We conclude by recommending further studies of surgical delivery that might reduce the cost to patients in both time and money, such as village-based surgery. We also recommend both cost-effectiveness and quality-of-life studies to investigate the potential benefit of surgery to patients in terms of their ability to work and their economic productivity—factors that seem to be important in influencing the decision to attend for surgery.

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