Distribution Agreement

Signature:

________________________________ _______________

Stephanie Lynn Palmer Date

“A Living Death”: A Qualitative Assessment of Quality of Life among Women with Severe Trachoma in Rural Niger

By

Stephanie Lynn Palmer
MPH

Hubert Department of Global Health

____
Kate Winskell, PhD, MA
Committee Chair

____
Paul M. Emerson, PhD, MSc
Committee Member

“A Living Death”: A Qualitative Assessment of Quality of Life among Women with Severe Trachoma in Rural Niger

By

Stephanie Lynn Palmer

Bachelor of Arts
Cornell College
2001

Thesis Committee Chair: Kate Winskell, PhD, MA

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Hubert Department of Global Health
2013

Abstract

"A Living Death": A Qualitative Assessment of Quality of Life among Women with Severe Trachoma in Rural Niger

By Stephanie Lynn Palmer

Background: Trachoma causes visual impairment and blindness, but even prior to vision loss, evidence suggests that it has a profound effect on women's abilities to lead a normal life. However, standard burden of disease measures, such as DALYs, fail to take this into account. In order to address this, we assessed the effects of trichiasis on the ability of women in rural Niger to live a quality life. We also examined the effects of trichiasis surgery on quality of life, and the process whereby women decide whether to seek surgery for trichiasis.

Methods: In-depth semi-structured interviews were conducted with operated and unoperated women and a friend of their choosing. Heads of households of women with trichiasis were also invited to participate in separate focus group discussions to contribute contextual information.

Results: A total of 23 women (13 operated and 10 unoperated) were interviewed and four focus groups were held in six villages. Women defined quality of life in terms of health, security, family and community, social status and fulfillment of religious obligations. Trichiasis profoundly affected quality of life by causing social withdrawal and exclusion, severe pain and physical disability, and inability to work and earn an income. This leads to loss of social status for these women and burdens the family with additional work and expenses. Surgery improves quality of life in almost all cases; the improvement extends beyond clinical improvement. Women generally make their own decision to be operated without pre-planning or forethought when surgical camp opportunities arise, though some still face obstacles preventing them from accessing surgery.

Conclusions: Trichiasis has a profound and disabling effect on most women, even those with less severe symptoms. While women in rural Niger often live in extreme poverty, trichiasis exacerbates the situation for these women personally, by causing physical disability and undermining their social status. It also adds to family burden, as women lose the ability to meaningfully contribute to the household and instead require additional family resources for their care. This should be reflected in the burden of disease attributable to trachoma in the DALY calculations currently under revision.

“A Living Death”: A Qualitative Assessment of Quality of Life among Women with Severe Trachoma in Rural Niger

By

Stephanie Lynn Palmer

Bachelor of Arts
Cornell College
2001

Thesis Committee Chair: Kate Winskell, PhD

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Hubert Department of Global Health
2013

Acknowledgements

I would like to express my sincere thanks and gratitude to a long list of people, without whom finishing this degree and thesis would not have been possible:

Dr. Paul Emerson, who provided me with the opportunity to carry out this study, as well as continual advice and encouragement over the last four years at The Carter Center.

Dr. Kate Winskell, for her support, encouragement and interest in my research, as well as for setting deadlines and making me stick to them.

Dr. Amy Patterson, for her assistance in organizing my thoughts and in developing study aims and methods.

Dr. Kadri Boubacar, Deputy National Coordinator for Niger’s National Program for the Prevention of Blindness and Mr. Salissou Kané, Carter Center Niger Country Representative, for agreeing to allow me to travel to Niger and conduct this study, as well as for assistance in planning and carrying out the training and fieldwork. I would also like to thank the entire Carter Center Niger—Zinder office staff for facilitating the implementation of the study, particularly Mr. Tahirou Oungoila.

In addition, this work would not have been possible without Mrs. Ali Yaya of Niger’s Ministry of Health who conducted ocular examinations on all study participants; Mr. Ibrahim Namata and Mr. Fatahou Ibrahim, students at the National School of Public Health in Zinder for their hard work in conducting interviews; and Ms. Ramatou Hamani, Mr. Ali Morou, and Mr. Issoufou Abdoulaye for spending long hours transcribing the interviews.

I would also like to thank the Health Programs’ staff at The Carter Center, especially Mr. Aryc Mosher and Ms. Kelly Callahan, for their advice, encouragement and humor throughout my MPH coursework and thesis.

Thank you to Mom, Dad and Jenny for always supporting my decisions and providing encouragement.

Lastly, I would like to extend my gratitude to the Conrad N. Hilton Foundation through the Kilimanjaro Center for Community Ophthalmology for their financial support.

Table of Contents

List of Tables and Figures

Tables

Figures

Acronyms

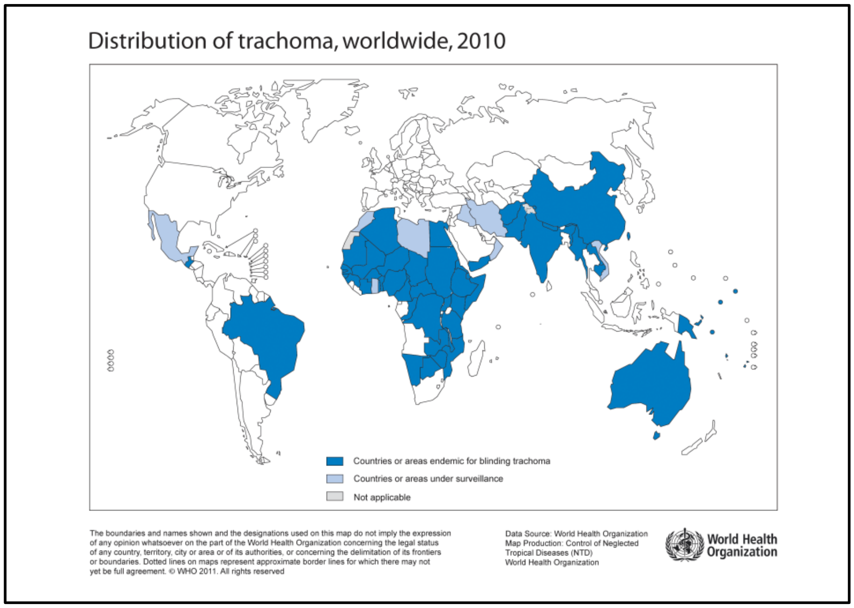
CO	Corneal Opacity
DALY	Disability-Adjusted Life Years
EQ-5D	EuroQol 5-D (Standarized questionnaire developed by the EuroQol Group to measure quality of life in 5 dimensions)
GET 2020	Alliance for the Global Elimination of Trachoma by the Year 2020
IOTAQOL	Standardized quality of life questionnaire developed by IOTA (*Institute d'Ophthalmologie Tropicale en Afrique*—African Institute of Tropical Ophthalmology)
PNLCC	*Programme Nationale de la Lutte Contre la Cécite* (National Program for the Prevention of Blindness
QOL	Quality of Life
SAFE	Surgery, Antibiotics, Facial leanliness and health education, Environmental improvements
SF	Short Form (questionnaire developed to measure quality of life)
TEO	Tetracycline Eye Ointment
TF	Trachomatous Inflammation Follicular
TI	Trachomatous Inflammation Intense
TS	Trachomatous Scarring
TT	Trachomatous Trichiasis
WHO	World Health Organization
WHOQOL	Standardized questionnaire developed by the WHO to measure quality of life
WHOQOL-Bref	Shortened version of the WHOQOL

1.0 Introduction

1.1 Trachoma

Trachoma is the leading cause of infectious blindness worldwide. It is endemic to 53 countries (Figure 1) where 325 million people are estimated to be at risk for the disease, and 7.2 million have the blinding form of the disease, known as trachomatous trichiasis (World Health Organization, 2012). Repeated ocular infections with the bacterium *Chlamydia trachomatis* lead to scarring of the conjunctiva of the inner eyelid. This scarring may eventually cause entropion—the in-turning of the lid margin towards the surface of the eye, causing eyelashes to turn towards and abrade the cornea. The abrasion leads to corneal damage, vision loss, and eventually, irreversible blindness (Pascolini et al., 2004; Rajak et al., 2011a).

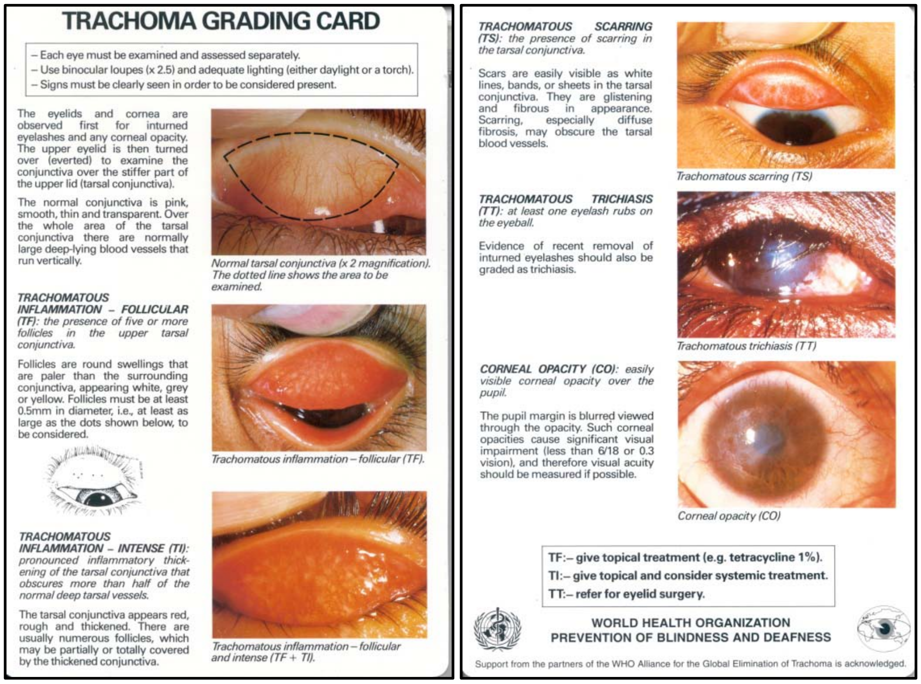
Figure 1. Worldwide Distribution of Trachoma, 2010



Chlamydia trachomatis is spread person to person via several routes: direct hand to eye contact; shared usage of fomites (clothing, towels); and the eye-seeking fly *Musca sorbens*, which comes in contact with infected ocular and nasal discharge (Emerson et al., 2004). Transmission of trachoma is associated with poor personal hygiene practices and lack of access to sanitation and water (Emerson, Bailey, Walraven, & Lindsay, 2001; Ngondi et al., 2007; Pruss, Kay, Fewtrell, & Bartram, 2002; Taylor et al., 1989; E. West et al., 2005). The reservoir of infection is believed to be children less than 10 years of age (Solomon et al., 2003), and infection is often clustered among children in the same household (Bailey, Osmond, Mabey, Whittle, & Ward, 1989; Burton et al., 2003; Taylor, et al., 1989).

Trachoma is a progressive disease, and classification of stages is made through the World Health Organization's (WHO) Simplified Grading System (Thylefors, Dawson, Jones, West, & Taylor, 1987). This system classifies the progression of trachoma into six distinct grades: 1) normal eyelid; 2) trachomatous inflammation – follicular (TF); 3) trachomatous inflammation – intense (TI); 4) trachomatous scarring (TS); 5) trachomatous trichiasis (TT); and 6) corneal opacity (CO). Trachomatous trichiasis, the advanced form of the disease, is defined as one or more lashes rubbing against the eyeball or evidence of recent epilation (removal of eyelashes). It should be noted that trichiasis is a general term to describe a wide spectrum of eye disease, from the very mild (no entropion and only one eyelash touching the outer corner of the eye) to complete entropion with the lid margin completely folded over and all lashes abrading the eye (Rajak, et al., 2011a). Figure 2 provides definitions for each grade and illustrates the progression from mild clinical signs of infection through blindness.

Figure 2. WHO Simplified Grading System



TRACHOMA GRADING CARD

- Each eye must be examined and assessed separately.
- Use binocular loupes (x 2.5) and adequate lighting (either daylight or a torch).
- Signs must be clearly seen in order to be considered present.

The eyelids and cornea are observed first for inturned eyelashes and any corneal opacity. The upper eyelid is then turned over (everted) to examine the conjunctiva over the stiffer part of the upper lid (tarsal conjunctiva).

The normal conjunctiva is pink, smooth, thin and transparent. Over the whole area of the tarsal conjunctiva there are normally large deep-lying blood vessels that run vertically.

Normal tarsal conjunctiva (x 2 magnification). The dotted line shows the area to be examined.

TRACHOMATOUS INFLAMMATION – FOLLICULAR (TF)*: the presence of five or more follicles in the upper tarsal conjunctiva.*

Follicles are round swellings that are paler than the surrounding conjunctiva, appearing white, grey or yellow. Follicles must be at least 0.5mm in diameter, i.e., at least as large as the dots shown below, to be considered.

Trachomatous inflammation – follicular (TF).

TRACHOMATOUS INFLAMMATION – INTENSE (TI)*: pronounced inflammatory thickening of the tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels.*

The tarsal conjunctiva appears red, rough and thickened. There are usually numerous follicles, which may be partially or totally covered by the thickened conjunctiva.

Trachomatous inflammation – follicular and intense (TF + TI).

TRACHOMATOUS SCARRING (TS)*: the presence of scarring in the tarsal conjunctiva.*

Scars are easily visible as white lines, bands, or sheets in the tarsal conjunctiva. They are glistening and fibrous in appearance. Scarring, especially diffuse fibrosis, may obscure the tarsal blood vessels.

Trachomatous scarring (TS)

TRACHOMATOUS TRICHIASIS (TT)*: at least one eyelash rubs on the eyeball.*

Evidence of recent removal of inturned eyelashes should also be graded as trichiasis.

Trachomatous trichiasis (TT)

CORNEAL OPACITY (CO)*: easily visible corneal opacity over the pupil.*

The pupil margin is blurred viewed through the opacity. Such corneal opacities cause significant visual impairment (less than 6/18 or 0.3 vision), and therefore visual acuity should be measured if possible.

Corneal opacity (CO)

TF:– give topical treatment (e.g. tetracycline 1%).
TI:– give topical and consider systemic treatment.
TT:– refer for eyelid surgery.

WORLD HEALTH ORGANIZATION
PREVENTION OF BLINDNESS AND DEAFNESS

Support from the partners of the WHO Alliance for the Global Elimination of Trachoma is acknowledged.

1.2 Elimination of Blinding Trachoma

In 1997, the first meeting of the WHO Alliance for the Global Elimination of Trachoma by the year 2020 (GET 2020) was held. In 1998, member states of the World Health Assembly adopted resolution 51.11 (http://www.who.int/blindness/causes/WHA51.11/en/index.html). Under this resolution, member states agreed to implement the full SAFE strategy with the aim of eliminating blinding trachoma as a public health problem: *Surgery* to correct entropion that causes lashes to abrade the cornea and leads to irreversible blindness; *Antibiotics* to treat active infection and reduce the reservoir of infection; and *Facial cleanliness* and *Environmental improvements,* including hygiene education and access to water and sanitation facilities, to prevent transmission of the disease (Emerson, Frost, Bailey, & Mabey, 2006).

The definition of elimination is nuanced and important to note: neither the organism *Chlamydia trachomatis* nor the advanced stage of trachoma, trichiasis, is being targeted for elimination. Rather, the goal is to eliminate blindness resulting from trachoma. That is, once the elimination targets have been reached, people still will become infected with *C. trachomatis* and people will still develop trichiasis. However, transmission of the disease will be low and the risk of incident trichiasis cases minimal, though national programs will need to ensure that systems are in place to detect and operate these cases before they lead to blindness.

In order for trachoma endemic countries to reach elimination, two proxy targets must be reached:

1. Prevalence of TF in children ages one to nine years must be less than 5% at the sub-district level (a sub-district is defined as an administrative or geographical unit with an approximate population of 50,000 inhabitants);
2. Prevalence of TT must be less than 0.1% in the total population.

1.3 Trachoma and Trichiasis in Women

While there is no evidence of an increased biological susceptibility to infection with *Chlamydia trachomatis* in women, research does indicate that females are more likely to carry high bacterial loads than males. Additionally, persistent infection or re-infection is more common in girls than boys, and women are more likely than men to be infected (Congdon, West, Vitale, Katala, & Mmbaga, 1993; Solomon, et al., 2003). Trichiasis presents more commonly in women than in men in every cross-sectional study published, and these studies attribute between 1.3 to 3.9 times excess risk of developing trichiasis in women than in men (Cromwell et al., 2009). This is generally attributed to women’s roles as caretakers of young children, the main reservoirs of the disease, and the subsequent increased exposure to infection (Congdon, et al., 1993).

1.4 Active Trachoma and Trichiasis in Niger

National surveys conducted in 1985 and 1989 determined that the overall prevalence of blindness in Niger was 2.2% and that trachoma accounted for 25% of this total. National trachoma prevalence surveys conducted from 1997-1999 revealed that over 36% of children ages 0-10 years of age had active disease (clinical grades TF and TI), and that 1.7% of women over the age of 14 had trichiasis (Ministère de la Santé Publique, 2006).

More recent surveys (2007-2012) carried out at the district level have shown that 22 out of 42 districts are currently endemic for trachoma, with TF prevalence ranging from 6-43% among children ages 1-9 years (Figure 3). Of the 22 endemic districts, 13 have a prevalence of trichiasis of >1% among adults ages 15 and above, the threshold at which enhanced surgical intervention is required (Figure 4).

Figure 3. Prevalence of TF among Children Ages 1-9 Years, Niger, 2012

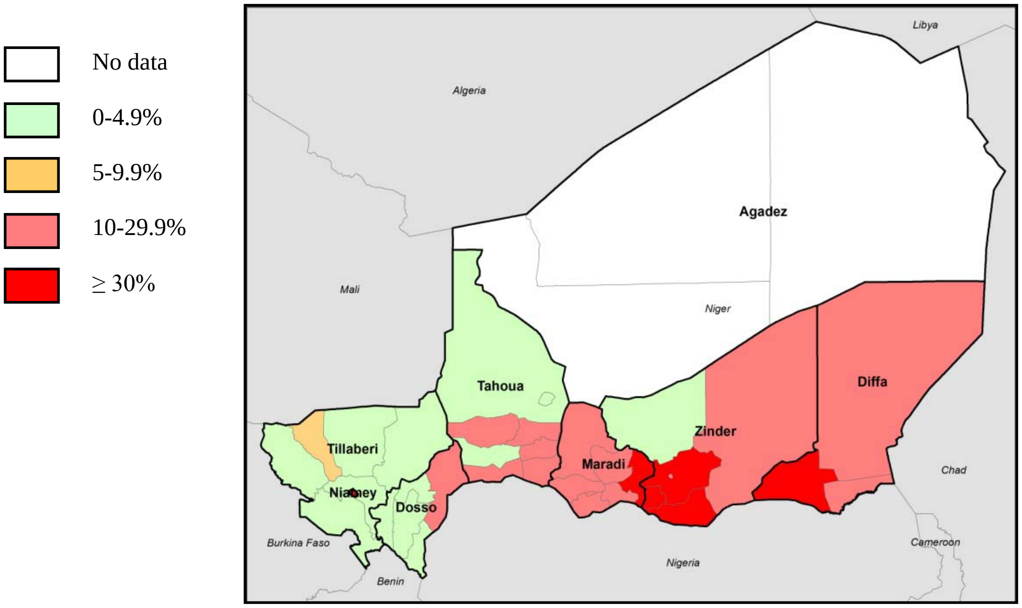
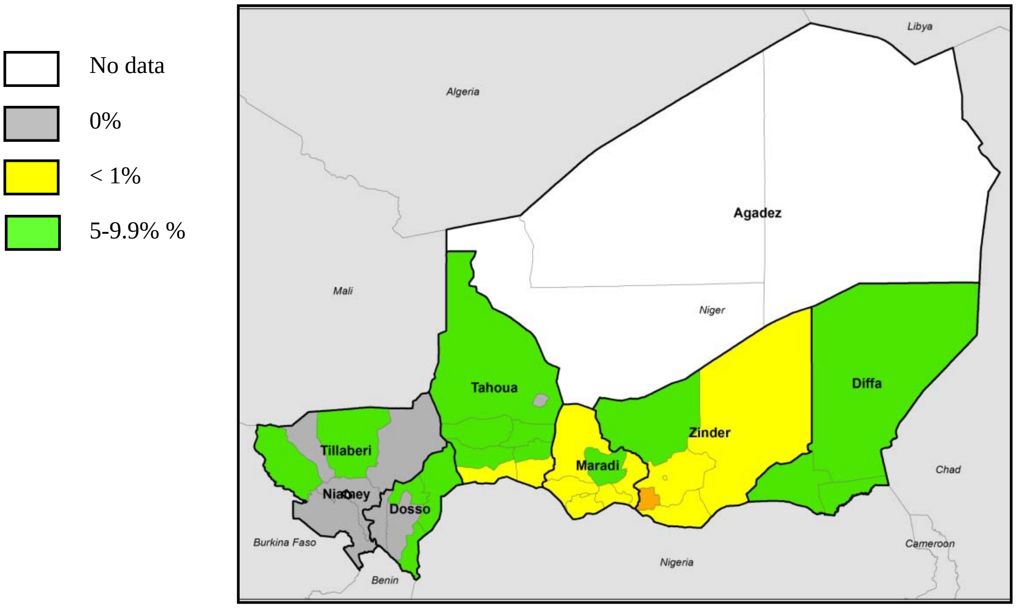
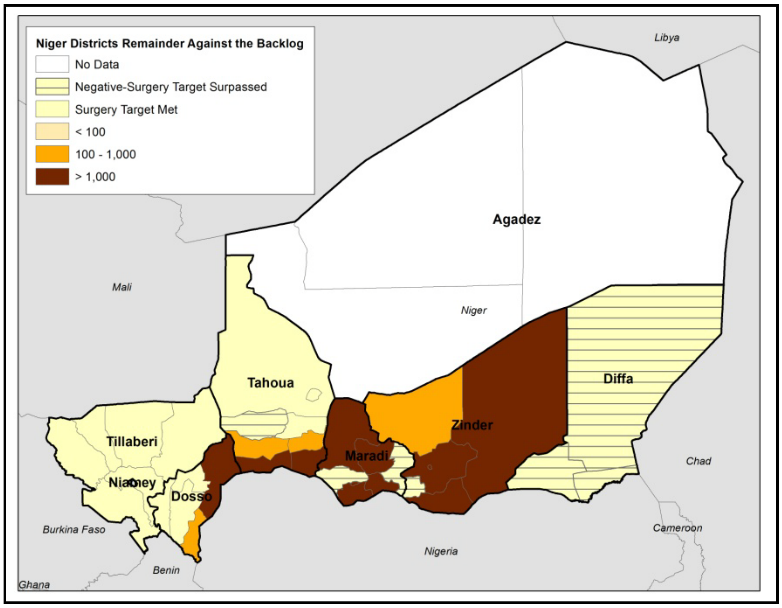


Figure 4. Prevalence of TT among Adults Ages 15 and Older, Niger, 2012



In 2012, Niger’s *Programme National de la Lutte Contre la Cécité* (National Program for the Prevention of Blindness (PNLCC)) calculated a backlog of approximately 33,000 trichiasis patients who need to be operated in order to reach the elimination target (Figure 5). Of this total, around 29,000 reside in the regions of Maradi and Zinder (Boubacar, 2013b). The PNLCC aims to eliminate blinding trachoma by 2015, and consequently, nearly all of these cases will need to be operated prior to the end of that year.

Figure 5. Estimated Trichiasis Backlog by District, December 2012



1.5 Trichiasis Surgery

Currently, the WHO recommends that all cases of trichiasis be operated, no matter the severity or degree of entropion (Reacher & Huber, 1998). The reasoning behind this recommendation is that trichiasis is a progressive disease, and patients presenting with a mild form may not return for surgery until the disease has progressed significantly, when their risk of blindness is consequently increased. Additionally, patients operated when their trichiasis is mild have a decreased risk of post-surgical recurrence than patients presenting with more severe trichiasis (S. West, 2011).

Eyelid surgery can be performed in health clinics and hospitals as part of the routine services offered or in outreach campaigns. Outreach campaigns may also take place at the village level, including in the patient’s house. The surgery is relatively simple, requires only a local anesthetic and takes approximately 15-20 minutes per eye. A recent population-based survey conducted in three countries (Mali, Niger, and Ethiopia) indicated that the majority of patients are operated during outreach campaigns (Palmer et al., 2012).

In Niger, when trichiasis surgery is performed as part of an outreach campaign, it is offered at no cost to patients. In addition, the PNLCC provides round-trip transportation for patients from their villages to the site of the surgical campaign. When surgeries are performed in clinics as part of routine services offered, patients are required to pay between 3-9 USD (1,500-4,500 CFA) per operated eye to cover the cost of consumables. This is viewed by the PNLCC as a cost-recovery mechanism and a way to ensure sustainability of the surgical program to operate incident cases post-elimination, although it is unclear whether the fees currently charged are being reserved for future trichiasis services.

In order to control potential post-surgical infection, patients are provided with a single oral dose of azithromycin and two tubes of topical tetracycline eye ointment (TEO) to apply to the eye twice daily for six weeks. Patients are also provided with acetaminophen tablets for pain relief and told to cleanse the surgical site with soap. Patients are required to return one week post surgery to have their sutures removed. While there is no fee for suture removal, patients are expected to return at their own expense.

1.6 Adverse Surgical Outcomes

Although entropion due to trichiasis can be corrected with surgery, recurrence under field conditions is common. A study in Tanzania showed that recurrence by district ranged from 16-38% two years post surgery (E. West et al., 2005). In The Gambia, a study indicated a mean recurrence rate of 41% at one year after surgery with a range of 0-80% by surgeon (Burton et al., 2005); and a study in Oman revealed a recurrence rate of 56% three years post surgery (Khandekar, Mohammed, & Courtright, 2001). Several unpublished studies in Niger indicate that recurrence is common but varies widely by geographical location. One study, which took place in the districts of Tessaoua, Aguié, Madaroumfa, and Guidan-Roumdji, showed that 29.1-62.2% (mean 42.2%) of patients presented with post-operative trichiasis approximately one year post-surgery (The Carter Center, 2010). However, an assessment which took place in the districts of Konni, Madaoua, Magaria and Mirriah revealed that 13.7 – 28.1% (mean 20.5%) of patients presented with post-operative trichiasis, though the survey did not record the length of time that had passed since surgery (Boubacar, 2013a). A third survey found that 33.7% of the entire sample presented with post-operative trichiasis, with the majority of those patients having received their surgery over three years prior to the survey (Palmer et al., 2012).

Causes of post-operative trichiasis and surgical complications can be grouped into three broad categories: surgeon skill, patient characteristics, and environmental factors. While the WHO has issued a standardized checklist of skills trichiasis surgeons must master prior to operating without supervision (S. West, Bedri, Ton, E. West, & Mariotti, 2005), this guide only provides general guidelines on skills and knowledge candidates must possess and recognizes that different eye health programs may have different standards for candidate selection and for surgeon training, including the number of surgeries that must be performed prior to final assessment and ability to perform surgery without supervision. It should also be noted that there is no requirement that national programs use the WHO final assessment tool, though it is recommended (International Coalition for Trachoma Control, 2012). In addition, this manual was only recently (2012) officially translated into French and circulated to francophone countries for use, though some countries, such as Niger, have been using an unofficially translated version of the assessment checklist for several years.

Patient characteristics associated with post-operative trichiasis include older age, presenting with trachomatous inflammation intense (TI) at time of surgery (E. West et al., 2005), previous trichiasis surgery, and more severe trichiasis and/or entropion when initially presenting for surgery (S. West, 2011). Certain genetic factors may also make a patient more likely to experience recurrent trichiasis (Burton et al., 2012). Some studies have shown higher recurrence rates in women than in men. Possible reasons include: women may have more severe trichiasis than men before seeking surgical services and they may utilize these services less frequently or have less access to them (Congdon, et al., 1993; Courtright & West, 2004; S. West, 2011). In addition, once patients undergo surgery, they return to their home environments, where there may be inadequate water or hygiene practices to maintain the cleanliness necessary to promote healing (S. West, 2011).

A randomized control trial in Ethiopia demonstrated that a single oral dose of azithromycin after surgery can reduce the likelihood of recurrence by 30% when compared to the standard regimen of topical tetracycline eye ointment applied twice daily for six weeks (S. West et al., 2006).

However, this study was unable to show that infection with *C. trachomatis* was a risk factor for recurrence. This could have been due to infections occurring between data collection periods or because of azithromycin's ability to target a broad spectrum of bacteria, decreasing the likelihood of secondary infection from bacteria other than *C. trachomatis* (S. West, 2011). Azithromycin also has anti-inflammatory properties, which may prevent the over-production of scar tissue after surgery, which also may lead to recurrence (Amsden, 2005).

1.7 Measuring the Burden of Trachoma

Initial trachoma mapping and impact studies are undertaken to measure the prevalence of TF and TT, the clinical presentations of trachoma that serve as proxy targets for the elimination of blinding trachoma. However, these studies are not designed to show any of the effects of the disease on individuals with trachoma or on communities where trachoma is endemic. One common way of trying to capture the overall burden of a particular disease is through standardized measures such as disability-adjusted life years (DALYs). DALYs measure the gap between a healthy population and the premature mortality (years of life lost) and disability (years lost due to disability) due to a particular disease (Murray et al., 2012). The motivation behind creating DALYs was threefold: 1) to identify health problems and their relative magnitude in order to prioritize investments in health research and resources for intervention; 2) to include morbidity as well as mortality in health policy debates; and 3) to conduct analyses on the cost-effectiveness of health interventions (Murray & Acharya, 1997).

The Global Burden of Disease study ranks the burden of disease for nearly 300 diseases and injuries. In 1990, this study estimated that trachoma was responsible for 144,000 DALYs; this estimate was increased to 334,000 in the 2010 update (Murray, et al., 2012). An analysis of DALYs in eye disease attributed 2.4% of the DALYs in low- and middle-income countries to trachoma (Ono, Hiratsuka, & Murakami, 2010). The major contributors to DALYs in these settings were refractive error (44.3%) and cataract (30.7%). However, while a much larger proportion of the population worldwide and in low- and middle-income countries have uncorrected refractive error and cataract than have trachoma, (cataract and uncorrected refractive error comprise nearly 60% of the global causes of blindness) (Johnson, Minassian, Weale, & West, 2012), neither is painful or stigmatized.

According to Burton and Mabey (2009), estimates for the burden of trachoma have several weaknesses: data on disease prevalence of disease in endemic areas are sparse (though increased trachoma mapping partially explains the increase in DALYs between 1990 and 2010); trichiasis itself is not included as a disabling sequela of trachoma separate from blindness and visual impairment, which may underestimate the burden of disease; and there is an absence of data as to what degree of premature mortality is due to trachoma.

The disability taken into account by the Global Burden of Disease studies is the disability due to blindness and visual impairment. However, a study conducted in Tanzania showed that trichiasis causes disability, even in cases where vision has not yet been affected, particularly in women (Frick, Melia, Buhrmann, & West, 2001). In addition, DALYs do not take into account lost productivity and disability prior to vision loss or the pain and stigma caused by trachoma, nor do they take into account the effects of the disease on whole families and communities. Studies such as the Global Burden of Disease study may be used by program funders and planners to determine where resources should be allocated; measures that do not assess the disease holistically may lead to a lack of advocacy surrounding the disease and resources appropriated to enable endemic countries to reach elimination.

1.8 Study Significance

Trichiasis is thought to have widespread consequences on individuals, families and communities. However, the evidence supporting this statement is scant. The little available evidence, largely anecdotal, suggests that at the individual level, trichiasis causes negative physical and psychological effects, such as pain, photophobia and social isolation (Litt, Baker, & Molyneux, 2012). At the family level, trichiasis patients may be unable to provide financially or perform household tasks to care for their families. Moreover, they may require care from their children, who then may miss the opportunity to attend school or use resources caring for their ill parents that would normally support the growth and development of their own children (International Coalition for Trachoma Control, 2011). At the societal level, lost productivity keeps a community in poverty (Frick, Hanson, & Jacobson, 2003), and women in particular may lose status, both as individuals and as a class if they are no longer be able to care for their children properly or perform other tasks for which they are responsible (Wolfson, Fedwa, & Young, 1997; The Carter Center, 2009).

Despite these far-reaching effects, much of the published literature on trachoma has focused on its prevalence and risk factors, as well as programmatic evaluations of the SAFE strategy. The three published studies available on quality of life (one evaluating overall quality of life and the two others evaluating physical functioning) indicate that trichiasis significantly affects physical and psychological health, particularly for women (Dhaliwal, Nagpal, & Bhatia, 2006; Wolle et al., 2011; Frick et al., 2001). However, these studies were conducted using quantitative quality of life instruments that were not designed specifically for those with trichiasis. While these instruments claim validity, they may not capture issues important to this population. In addition, there is a lack of published literature in which trichiasis patients themselves describe the effects of trichiasis on their lives. Finally, as described above by Burton and Mabey (2009), standardized measures of disease burden do not take into account trichiasis in the absence of blindness or visual impairment; however, there have been few published studies substantiating the call to include trichiasis itself as a morbidity resulting from trachoma.

1.9 Purpose Statement

This study was carried out to provide in-depth descriptive detail on how trichiasis affects the quality of life of rural Nigerien women with the disease. Its point of departure was to determine how these women define “quality of life.” The study also sought to assess whether surgery for trichiasis improves the quality of life of those operated and to examine the process whereby women make the decision to be operated for trichiasis and to identify barriers preventing women in this environment from being operated.

1.10 Study Questions

1. How do adult Nigerien women with trichiasis (operated and non-operated) define quality of life?
2. How do these women perceive their quality of life?
3. How does surgery affect these women’s quality of life and what aspects of life are affected?

4. How do these women make the decision to be operated for trichiasis?

5. What barriers prevent women in this environment from seeking or accessing surgical services?

2.0 Literature Review

2.1 Quality of Life

The World Health Organization defines health as "A state of complete physical, mental and social well-being, not merely the absence of disease…" (World Health Organization, 1997). It follows that healthcare should include not only services to prevent, cure, and treat disease, but should also take a holistic approach to the well-being of individuals. In recent years, a broad array of quantitative instruments to assess quality of life has been developed. Certain instruments are designed to measure general quality of life; others are disease or condition-specific. Those focusing on specific conditions or diseases often focus on disability resulting from the condition or disease or are used as tools to evaluate treatment outcomes (Carr, Higginson, & Robinson, 2003).

2.1.1 Quality of Life Instruments

2.1.1.1 WHOQOL-100 and WHOQOL-Bref

The WHOQOL-100 and WHOQOL-Bref were designed to measure the quality of life in diverse populations. The WHOQOL is a 100-item instrument that measures 24 facets of six domains as indicators of quality of life (World Health Organization, 1997). The WHOQOL-Bref consists of 26 items, one question taken from each of the WHOQOL-100 facets, plus two questions addressing overall quality of life (World Health Organization, 2004). The six domains are:

1) physical health, which includes questions about physical pain, energy, and sleep;

2) psychological health, which includes questions about body image, positive and negative feelings, self-esteem, and thinking, memory and concentration;
3) level of independence, which includes questions about mobility, activities of daily living, dependence on medication and other medical aids, and work capacity;
4) social relationships, which includes satisfaction with personal relationships, sex life and social support;
5) environment, which includes safety, finances, access to information, leisure activities, living conditions, access to health services, and transportation; and
6) spirituality/religion, which includes questions about personal beliefs.

Although these instruments are purportedly well-validated and reliable, only one African country (Nigeria) was included in the testing phase. These tools measure items only pertinent to an individual; in more communal societies, family factors may be equally or more important (Carr, et al., 2003). Additionally, some items may not be appropriate in certain settings or relevant to the condition of interest. For example, the standard question, "How satisfied are you with your sex life?" may not be appropriate in conservative or religious settings, such as Niger, or relevant to elderly trichiasis patients.

2.1.1.2 EQ-5D

The EQ-5D is a standardized instrument used to measure health outcomes over time (EuroQOL Group, 2009). For example, the instrument could be administered to patients before an intervention, and then at some (or several) point(s) after the intervention. The instrument uses five items to measure the following five domains: 1) mobility; 2) self-care; 3) usual activities; 4) pain/discomfort; 5) anxiety/depression. For each of the five items, patients are asked to select the response that best describes their health on the day the instrument is administered. Responses range from no problems to extreme problems. Patients are then asked to rate their overall health on a scale from 1-100.

This instrument is quick to administer and is specifically designed to measure perceived health over time. However, the domains are extremely limited and individualistic in scope and may not capture aspects considered important to quality of life in all populations. Additionally, patients in some settings may be unfamiliar with the 1-100 scale format, and patients with similar clinical pictures may have vastly different perceptions about the degree of difficulty they have in a given domain.

2.1.1.3 Medical Outcomes Study Instrument

The Medical Outcomes Study was designed for two specific purposes: 1) to determine whether variations in patient outcomes are explained by differences in system of care, clinician specialty, and clinicians' technical and interpersonal styles; and 2) to develop more practical tools for the routine monitoring of patient outcomes in medical practice (Tarlov et al., 1989). The original instrument was a 116-item questionnaire developed to measure longitudinally the health of persons suffering from chronic diseases. The instrument measures eight aspects of general health, physical health, and psychological health: 1) health and daily activities; 2) physical health; 3) pain; 4) daily activities; 5) feelings; 6) social activities; 7) health; 8) sleep.

This questionnaire is long and many of the sections overlap; consequently, many shorter questionnaires were developed out of this study, such as the Short-Form 12 (SF-12), SF-20, and the SF-36 (the numbers denoting the number of questions on the questionnaire). Some of these abbreviated instruments have been translated into other languages and tested in other settings; however, none have been translated into African languages or tested in African countries (IQOLA Project, 1990).

2.1.1.4 Visual Functioning Questionnaires

Visual function is a measure of a person's ability to perform activities of daily living affected by vision (van Dijk et al., 1999). Numerous instruments that measure visual function have been developed and tested in a variety of settings. Questions may revolve around difficulty (or ease) in reading printed materials, performing work or hobbies requiring one to see objects at close range, reading street signs or seeing people or objects at a distance, mobility, and social situations. While many of these items may be adaptable to populations in developing nations, these instruments may not be applicable to trichiasis patients, as certain patients may not have experienced changes in visual acuity, and certain items, such as those involving close vision (reading, writing), may not be relevant in a mostly illiterate population.

2.1.1.5 IOTAQOL

An instrument known as the IOTAQOL, was developed in Mali to measure quality of life in blind and partially sighted patients among the ethnic populations of that country, specifically, the Bambara, Fulani and Bozo (Leplège et al., 2006; Schémann, Leplège, Keita, & Resnikoff, 2002). However, trichiasis is responsible for only a proportion of all blindness, and it is not known whether trichiasis patients were interviewed during the formulation of this instrument. Additionally, trichiasis patients may suffer disability and quality of life issues beyond those of patients with just low vision or blindness resulting from other causes (Frick et al., 2001).

2.2 Quality of Life Studies in Populations with Diseases of the Eye or Visual Impairment

The majority of studies looking at quality of life in patients with eye disease have done so with visual impairment due to sources other than trichiasis, such as cataract. While surgical interventions are available for both cataract and trichiasis, cataract surgery may result in a re-gaining of vision and visual function with the removal of the cataract; vision loss due to corneal damage sustained in trichiasis cannot be restored. Not all trichiasis patients lose visual function; however, trichiasis causes many effects beyond those of vision loss, such as pain, photophobia or social stigma that cataracts may not.

Only one previous study investigating overall quality of life in trichiasis patients was found during a search using PubMed Central (Dhaliwal et al., 2006). This case-control study in India used the WHOQOL-Bref questionnaire to assess quality of life in trichiasis patients with major and minor trichiasis before and after intervention and used cataract and refractive error patients as the control group. The intervention received by the cases (trichiasis patients) differed by severity of trichiasis. Those patients with major trichiasis (> 5 trichiatic lashes) were operated, while patients with minor trichiasis (5 or fewer trichiatic lashes) were epilated. The questionnaire was re-administered to trichiasis patients (cases) one month following surgery and 15 days following epilation.

In the analysis, the WHOQOL facets (described above) were grouped into four domains: 1) physical health, including questions on activities of daily living, dependence on medication, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity; 2) psychological health, which includes questions on body image and appearance, negative and positive feelings, self-esteem, spirituality and religion, thinking, learning, memory and concentration; 3) social relationships, including personal relationships, social support, and sexual activity; and 4) environment, with questions relating to financial resources, freedom, physical safety, and health and social care.

Among study participants with poor vision, the survey found poorer quality of life among cases than controls in two out of four domains (physical and psychological health); among study participants with normal vision, the study found poorer quality of life among cases than controls in three out of four domains (physical, psychological and environmental). The survey also found significant improvements in physical and psychological health and environment post-intervention in both case groups.

There are several limitations to this study. First, the categories used in the analysis are broad, and it is unclear what aspect of a given category was affected by trichiasis (e.g. for psychological health, were patients primarily concerned with their body image/appearance or with ways in which trichiasis impeded their ability to practice their religion?). Another limitation of this study is that it is not clear that an appropriate control group was chosen. Cataract and refractive error occur in all socio-economic groups, whereas trachoma occurs only among the poorest of the poor (Wright, Turner, & Taylor, 2007). The study stated that it controlled for socio-economic status, but the authors do not state what indicators were used as proxies, and in settings where socio-economic status cannot easily be quantified, proxies must be chosen carefully. Additionally, this study took place in a university eye clinic, suggesting that study participants had at least the means and desire to travel and self-report at the university clinic for care; many trichiasis patients are unable or unwilling to travel to clinics, either due to the direct or indirect costs involved, anxiety/fear or mobility and transportation issues. Finally, the follow-up surveys were administered either 15 days or one month post-intervention, so long-term improvements in quality of life are unknown, especially for those patients who were epilated, as trichiatic lashes will grow back.

A second study aimed to examine physical disability among trichiasis patients in Tanzania (Frick et al., 2001). Men and women over the age of 40, with and without trichiasis, were randomly selected for participation. Participants were given ocular clinical examinations, including tests of visual acuity, and were administered standardized questionnaires with questions on the degree of difficulty they had in performing activities such as visiting with neighbors, walking outside the village, farming, recognizing faces, cooking, bathing, and dressing. The study found that regardless of visual acuity, women with trichiasis had difficulty with a greater number of tasks than women without trichiasis, and women with trichiasis and no visual acuity loss had difficutly with a similar proportion of tasks as women with visual acuity loss and no trichiasis. In men, trichiasis in the absence of visual acuity loss was not associated with more difficulty compared to having neither trichiasis nor visual acuity loss.

While this study sheds light on the effects of trichiasis on physical functioning and indicates that the effects are greater among women than men, it does not address other aspects of quality of life, such as the social and economic effects for the individual, nor is it able to address any communal effects of the disease.

A final study evaluated physical functioning among trichiasis patients before and after trichiasis surgery in Ethiopia (Wolle et al., 2011). The study found that two-thirds of patients had some degree of difficulty in physical functioning (e.g. walking around the village, recognizing faces, gathering and chopping wood, farming, grinding coffee, etc.) prior to surgery. However, in this study, there was no significant difference in difficulty between men and women. After trichiasis surgery, over 60% of participants experienced improvement in their physical functioning. Of those patients who reported no improvement, the majority had reported no difficulty at baseline. Improvements in physical functioning were associated with gains in visual acuity.

However, the scope of the questionnaire used was limited, and all improvements were presumed to be tied to improved visual acuity and not potential parallel improvements in social roles or psychological health.

2.3 Criticisms of Survey-Based Quality of Life Studies

While quality of life instruments may be useful to measure a person's quality of life at a moment in time or at multiple time points, especially as an indication of the effectiveness of a surgery or intervention, there are several main criticisms of these survey-based instruments:

1) Quality of life is a subjective construct. Some patients perceive their quality of life as poor, despite good clinical prognoses or mild or no disease, while others, with poor prognoses or severe disease, may perceive their quality of life as high.

2) Instruments may not take expectation into account. When measuring quality of life before and after an intervention or treatment, certain people have high expectations for health outcomes. If the treatment went poorly, then the impact on quality of life may be great; contrarily, if the person's expectations were low and the outcome was poor, perceived quality of life may not be affected.

3) Quality of life instruments may not measure what is most important to the patient. Formative research may not have been conducted to determine what items should be included in the instrument, and these items may change based on the study setting.

4) Quality of life instruments are targeted at the individual. Formulators of instruments may not take into account the fact that in many settings, the quality of life of an individual depends on a larger construct, such the family or community (Carr et al., 2003).

2.4 Decision-Making

A substantial body of literature exists on household decision-making in Africa, especially the role women play in making or influencing these decisions. A number of factors influence a woman's level of authority within the household, including age, marital status, culture/ethnicity, income level, and level of education (Angel-Urdinola & Woden, 2010). Income level alone, however, is not as important as women’s ability to control their income and use it as a leveraging tool to influence decisions made within the household (Duflo, 2012).

2.4.1 Decision-Making for Healthcare

2.4.1.1 Preference for Traditional Treatment

Across Africa, before seeking treatment at biomedically-focused health centers, patients may often turn to traditional treatments. The reasons patients choose to do this include: trust in traditional healers, including the perceived quality of care; cost, as treatments from healers may be less expensive than those from health centers, and healers may only demand payment once the condition has been resolved or accept in-kind payment instead of cash; and proximity and wait time, as the distance to travel may be shorter and patients may not have to wait in line for care as they do in health centers (Courtright, Chirambo, Lewallen, Chana, & Kanjaloti, 2000).

To manage their trichiasis prior to seeking surgical services, many patients consult with healers and are given concoctions made from plants and herbs to apply to their eyes or amulets to wear. Others manage their trichiasis using treatments such as epilation, burning the lashes with hot coals or cutting the lashes with scissors (Rajak, Collin & Burton, 2012).

2.4.1.2 Epilation as a Management Strategy for Trichiasis

In 2012, the World Health Organization and the Kilimanjaro Centre for Community Ophthalmology held a joint meeting to discuss available evidence on trachomatous trichiasis, including the management of trachomatous trichiasis. Currently, the WHO recommends that surgery be offered to all patients with trachomatous entropion trichiasis[1]. Indications for surgery, surgical techniques and outcomes, administration of post-operative antibiotics, and types of sutures were some of the topics covered during this meeting. In addition, this group discussed the role of epilation in trichiasis management. The meeting report states:

> Programs need to place the patient in the center of the decision-making process and consider options beyond surgery. Patients with symptoms and access to affordable, high-quality TT services are generally more willing to accept surgery. For many, epilation is very popular and widely practiced as it relieves symptoms. Epilation appears to be an alternative in certain circumstances, specifically, for minor TT when high-quality forceps and training on their use is available (International Coalition for Trachoma Control, 2012).

Some national programs already recommend epilation for cases of minor trichiasis (Reacher et al., 1998). However, there is little in the published literature about patients' perceptions of or preferences for epilation as a treatment option, though a randomized controlled study in Ethiopia allocated patients to arms to receive surgery or epilation to determine whether epilation was noninferior to surgery. While the results were inconclusive, patients in the epilation arm were offered surgery at follow-up, and only 31% accepted (Rajak et al., 2011b). The interpretation of this finding is that the patients who refused surgery preferred to epilate.

---

[1] Trachomatous entropion trichiasis is defined by the physical in-turning of the eyelid margin causing the eyelashes to abrade the eye; trichiasis simply refers to the abnormal positioning of the eyelashes from any cause.

2.4.1.3 Barriers to Seeking Trichiasis Surgery

While there is a tendency for patients to seek out traditional treatment prior to turning to surgery, when patients do desire surgery, barriers may prevent them from actually accessing the surgery. Various studies looking at surgical uptake have made estimates that between 18-66% percent of trichiasis patients access surgery within follow-up periods ranging from 1-2 years in Tanzania and The Gambia (Bowman et al., 2002; Bowman et al., 2000; Mahande et al., 2007; S. West et al., 1994). Factors influencing surgical uptake are generally divided into three broad categories: awareness, acceptance and access (The Carter Center, 2009). In order to address the discrepancy between available surgery and lack of uptake, multiple studies carried out in various settings have focused on issues related to access. Although the most important barriers varied by country, some of the most common factors associated with not presenting for surgery include financial or time constraints; lack of an escort to the surgical site; mild or no symptoms; fear of surgery; lack of information about the time/place of the surgery; small children at home; and lack of transport/distance to surgical site (Bowman, et al., 2002; Oliva, Munoz, Lynch, Mkocha, & West, 1997; Rabiu & Abiose, 2001; Rajak, Habtamu, Weiss, Bedi, Zerihun, et al., 2012; S. West et al., 1994). Another explanation for this is that patients are content with their current management practice, such as epilation, which is popular and well-regarded in many settings (Rajak, Collin, & Burton, 2012).

Many of these barriers have been addressed by national trachoma control programs. Often, surgical campaigns are organized at the village level where surgery is offered free of charge. This strategy eliminates or reduces the barriers of financial constraints, the need to find an escort, and the lack of transportation. Some trachoma control programs also address the information barrier by using local radio stations to broadcast information about the time, date and place of surgical camps. However, from the low uptake of surgery reported above, it is apparent that not all of these barriers are being adequately addressed, or perhaps other barriers have not yet been identified.

As discussed previously, women are more likely than men to develop trichiasis and therefore, more likely to require surgical services. Noting this fact, a number of publications have advocated that trachoma control programs systematically and deliberately target women for surgical services (Cromwell, et al., 2009; The Carter Center, 2009). While one study conducted in Tanzania and Vietnam has shown that at least in these two countries, services were being provided equitably to both sexes based on their proportionate burden of trichiasis (S. West et al., 2004), scant literature has reported on this in other settings. However, while there have been numerous studies looking at barriers to patients needing to access trichiasis surgical services, we were unable to find anything in the published literature looking at the decision-making process, and none of the studies looking at barriers were conducted in the location addressed in this study: rural Niger. Better information about this process and barriers particular to patients in this setting will enable the PNLCC to better address patient needs in the provision of surgery.

2.5 Summary

Many quantitative quality of life instruments are currently available; however, quality of life is, by nature, a subjective construct, and these tools may not capture the most salient aspects of a quality life for women with trichiasis. In addition, the concept of a quality life is not always concentrated on the individual and surveys rarely take into account communal aspects of life.

The three studies described above (Dhaliwal et al., 2006; Frick et al., 2001; Wolle et al., 2011) on overall quality of life and disability/physical functioning in trichiasis patients both used quantitative tools, and subsequently, detail and description of the effects of trichiasis on a life of quality are absent.

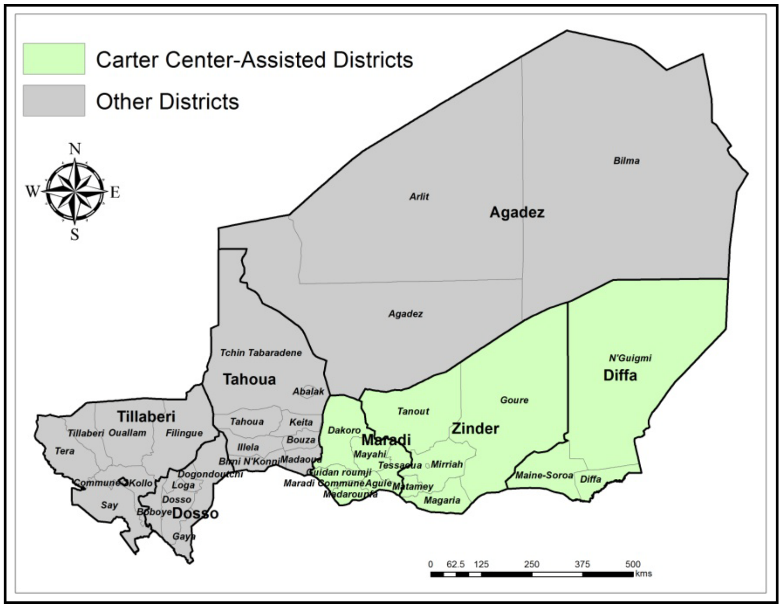
Because the present study focuses on the quality of life of operated and non-operated women with trichiasis, it also must address why some women remain unoperated. The available literature consists of many studies looking at barriers to accessing surgery, though none of these studies address the decision-making process itself, and little information is available on barriers specific to this population. This study, therefore, seeks to determine qualitatively how trichiasis affects quality of life among women with trichiasis, how the surgery affects quality of life, and to determine how women make the decision to receive surgery and what barriers still keep patients from seeking or accessing surgical services in rural Niger.

3.0 Methods

3.1 Introduction

This study is original qualitative research designed to examine the effects of trichiasis on quality of life in adult women (ages 18 and older) with current or former trichiasis in the Zinder and Maradi regions of Niger. This study was conducted by The Carter Center Niger through its partnership with Niger's National Program for the Prevention of Blindness. With financial and technical assistance from The Carter Center, the PNLCC aims to eliminate blinding trachoma by 2015. Since 2008, The Carter Center has assisted the PNLCC to implement the full SAFE strategy to eliminate blinding trachoma, including the provision of surgical services (Figure 6).

Figure 6. Districts Receiving Support from The Carter Center



3.2 Study Site

3.2.1 Background

Niger is a landlocked country in sub-Saharan Africa (Figure 7) whose economy centers on subsistence crops, livestock, and natural resource exploitation, such as oil and uranium. Ranked 186th out of 194 countries in the Human Development Index (Malik, 2013) the survival of much of the population has become more tenuous through cycles of drought and famine since the 1970s. Niger lacks much basic infrastructure, including adequate health services, to prevent and treat disease (CIA, 2013).

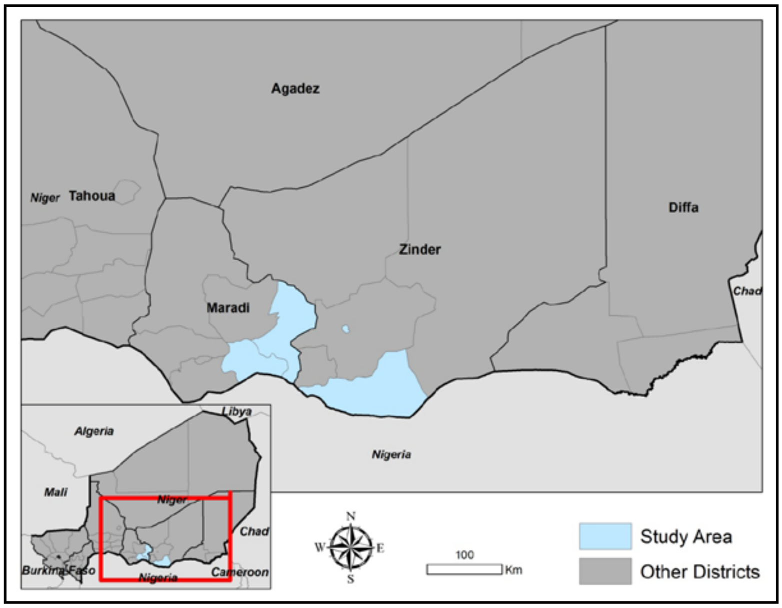
Figure 7. Niger's Geographical Placement in Africa

3.2.2 Study Population and Setting

This study was conducted in six villages in four districts: four villages in two districts (Zinder Commune and Magaria) in the region of Zinder and two villages in two districts (Tessaoua and

Aguié) in the region of Maradi (Figure 8). Zinder and Maradi are located in the eastern part of Niger and border on northern Nigeria. The majority of the population are from the Hausa ethnic group, with Touareg, Kanouri, and Peuhl groups in the minority.

Figure 8. Districts Included in Study



3.3 Field Work

3.3.1 Study Team

The study team consisted of eight members: the author; two public health students with considerable field experience from the *École Nationale de la Santé Publique* (National Public Health School) in Zinder; a trained and currently active trichiasis surgeon employed by the Ministry of Health; a Carter Center Niger staff member trained as a *Technicien Superieur en Ophthalmologie* (Superior Technician in Ophthalmology) ; and three transcriptionists from the *Direction Régionale de la Santé Publique* (Regional Directorate of Public Health). All study team members were fluent in French and familiar with the local culture, and all except the author were fluent in Hausa, the language in which the study was to be conducted.

3.3.2 Training

A three-day theoretical and practical training for the study team members who were to be collecting data took place before the start of data collection. The author trained the other members of the study team, in collaboration with The Carter Center's Country Representative in Niger; The Carter Center's Program Officer in Zinder; and the Deputy National Coordinator of the PNLCC. Theoretical topics included an overview of trachoma; an introduction to the concept of quality of life; research ethics and confidentiality; and qualitative research methods and interviewing techniques. The third day of the training was spent in the field practicing interviewing techniques and ensuring that the interview guides were understood by the target population. A separate one-day training was held after the commencement of data collection for the transcriptionists. This training focused on confidentiality of the data; standardized transcription format; and translation of colloquial phrases and accompanying explanations.

3.3.3 Village Selection

A list of all villages from which at least one trichiasis patient was operated in 2011 was compiled and listed by district and region in Excel. The list was then randomized by assigning each a random number using the RANDOM function in Excel and sorting the list numerically from low to high. Villages were visited in the order on the list. If a village was found not to be suitable for reasons such as accessibility or security, then the next village in the same district was visited. Villages were visited until data saturation had been achieved. Data saturation was defined as the point at which no new themes emerged from the interviews and focus group discussions. At the conclusion of each day, study team members met to discuss important points of each interview and focus group to ascertain whether new information had been captured in order to determine whether additional interviews or focus groups were required.

3.3.4 Participant Recruitment

3.3.4.1 Operated and Unoperated Trichiasis Patients

Community health workers asked all adult (ages 18 or older) women currently living with trichiasis or who had previously received eyelid surgery to report to a central location, generally the residence of the village chief or outside the village mosque. After obtaining informed consent, a trained trichiasis surgeon then examined each patient and completed a form with demographic and clinical characteristics for each patient (Appendix I). Women with an ocular co-morbidity, such as cataract, were excluded from participation. Each woman who was not excluded then participated in unrecorded focus group discussions about trachoma. Questions focused on knowledge of the disease and perceptions of the surgery. Those women who actively responded to questions and who had specific clinical characteristics were asked to participate in an in-depth interview. If they accepted to participate, they were asked to choose a female friend or confidante age 18 or older to join them in the interview (Patterson, 2012). This methodology of paired interviewing was employed in order to provide moral support, as the study team anticipated that the women may be anxious and withdrawn in a one-on-one interview format. Demographic information was collected on each friend/confidante (Appendix II). Informed consent to interview and to record the interviews was then obtained from each pair of women.

Interviews were held in a private location of the participants' choosing. It was estimated that 10-15 interviews each would be needed with operated and unoperated women with trichiasis in order to reach data saturation.

3.3.4.2 Focus Group Participants

Community health workers were asked to identify all adult (age 18 and over) male heads of households for operated and unoperated women with trichiasis in their villages (Appendix III). Selection of participants was not restricted to heads of households of the female trichiasis patients participating in the in-depth interviews. These heads of household were then administered a standard questionnaire to obtain demographic information and to ensure that they were aware of their family member's diagnosis, understood that trichiasis was operable, and knew where surgery was offered. Six to ten heads of household were required in any one village in order to conduct a focus group discussion. It was estimated that three to five focus groups would be needed to reach data saturation. Focus group discussions took place in a semi-private location in a central area, either near the central mosque or the village chief's home.

3.4 Data Collection

3.4.1 Study Procedure

In-depth interviews and focus group discussions took place in the local language, Hausa. Interviews and focus groups were recorded with digital audio recorders and later transcribed into French. During the in-depth interviews, a single interviewer asked questions and took notes, while during the focus group discussions, one interviewer asked questions, while the second interviewer was employed to take notes. Following the interviews and focus groups, the study team met to discuss the key findings in order to include additional lines of query or follow-up questions in subsequent interviews.

3.4.2 Study Instruments

Semi-structured interview guides were developed for in-depth interviews with operated and unoperated women and for focus group discussions with heads of households (Appendices IV-VI). Questions were categorized into four main themes: 1) definition of a quality life; 2) how trichiasis did or did not affect this ideal; 3) how surgery affected pre-surgical quality of life and perceptions of trichiasis surgery; and 4) the decision-making process, including factors influencing health-seeking behaviors and presenting for trichiasis surgery. Interview guides were developed in French, discussed by the study team and translated into Hausa, before being back-translated by an independent person to ensure quality translation. Study instruments were pre-tested in a non-study village during the training phase. Interviewers were asked to follow the interview guides and ask follow-up questions and probes based on participant responses. For the in-depth interviews, interviewers were instructed to direct questions to the woman with operated or unoperated trichiasis and ask her friend/confidante to confirm or add to statements made by the trichiasis patient.

3.5 Data Analysis

3.5.1 Transcription

Audio recordings were transcribed by Ministry of Health staff fluent in Hausa and French who received a one-day training in transcription methodology. Transcriptionists were asked to transcribe the recordings verbatim into French and to translate colloquial phrases in a consistent manner. To improve the accuracy of the transcription, early in the transcription process, the interviewers were asked to listen to three of the recordings and simultaneously read the French transcription. Discrepancies were noted and the interviewers reviewed any problems identified in the transcription with the transcriptionists. Transcriptions were de-identified prior to further analysis.

3.5.2 Coding

The de-identified transcripts were uploaded into MaxQDA 2010[2]. Deductive codes were identified, defined and entered into the codebook. After reading and re-reading the data, additional inductive codes were identified, defined, and entered into the codebook. Codes were applied to the transcripts. A PhD-level qualitative researcher who was not involved with the data collection and who is fluent in French and familiar with West African culture volunteered to apply the codes to a sub-set of the transcripts (six). Discrepancies in coding were then discussed, code definitions were adjusted, and transcripts were re-coded with the adjusted codes.

---

[2] VERBI Software, Berlin, Germany.

3.5.3 Analysis

Analytic memos were written throughout the readings of the transcripts to identify overarching themes, unclear text segments, and follow-up items, as well as commonalities and differences within and between interviews and focus groups. Codes related to each theme were grouped, and all text segments relating to an overarching theme were then extracted into separate Microsoft Word 2010[3] documents. Text segments relating to these themes were separated by strata (operated women, nonoperated women and focus groups) and again examined for commonalities and differences within and between strata. The unit of analysis used for the in-depth interviews was the patient-friend pair; however, quotations from friends were distinguished from those made by patients. The unit of analysis used for the focus group discussions was the focus group.

3.5.4 Verification

In order to ascertain that the findings identified in the analysis originated from the dataset, specific quotes from the transcriptions were matched with each key finding. Contradictory quotes were also sought out, and if found, all text segments relating to a theme were re-read and the finding was modified to include these cases.

3.6 Ethical Considerations

The study was reviewed and approved by the Emory University Institutional Review Board under eIRB #59282. Upon entrance to a selected village, study team members met the village chief and/or his advisors to explain the purpose of the study, the study procedures, and to ask for permission to conduct the study in the village. Study participants were told the nature of the

---

[3] Microsoft Corporation, Redmond, Washington.

study and the study procedures and asked for their verbal consent to participate prior to data collection. Verbal consent was documented on the questionnaire administered to each participant. Prior to in-depth interviews or focus group discussions, participants were asked to provide verbal consent for audio-recording of the interview or focus group. Forms were kept in secure offices and audio recordings were downloaded to password-protected computers each evening. Transcriptions were de-identified prior to analysis. Participants were not paid or offered gifts for participation. Participants with unoperated trichiasis, recurrent trichiasis, or other ocular morbidities were referred to the nearest health facility where services were available according to national guidelines. If active trachoma was detected (grade TF and/or TI), participants were given two tubes of topical tetracycline eye ointment and instructed to apply twice daily for six weeks to the eyes in accordance with national guidelines.

4.0 Results

4.1 Overview of Findings

Community health workers from six villages in four districts identified a total of 45 operated and nonoperated women (Figure 9). A clinical examination excluded three women due to the presence of an ocular co-morbidity. Forty-two women participated in informal focus groups, 19 of whom were excluded based on non-participation. A total of 23 women were selected for interview, 13 of whom had been previously been operated and 10 who had never been operated. Women with a variety of ages (range: 20-90), time since surgery (three months-25 years) and clinical presentations were selected for interview (Table 1). The average duration for each in-depth interview was 45 minutes.

Figure 9. Process Flow of Participant Selection

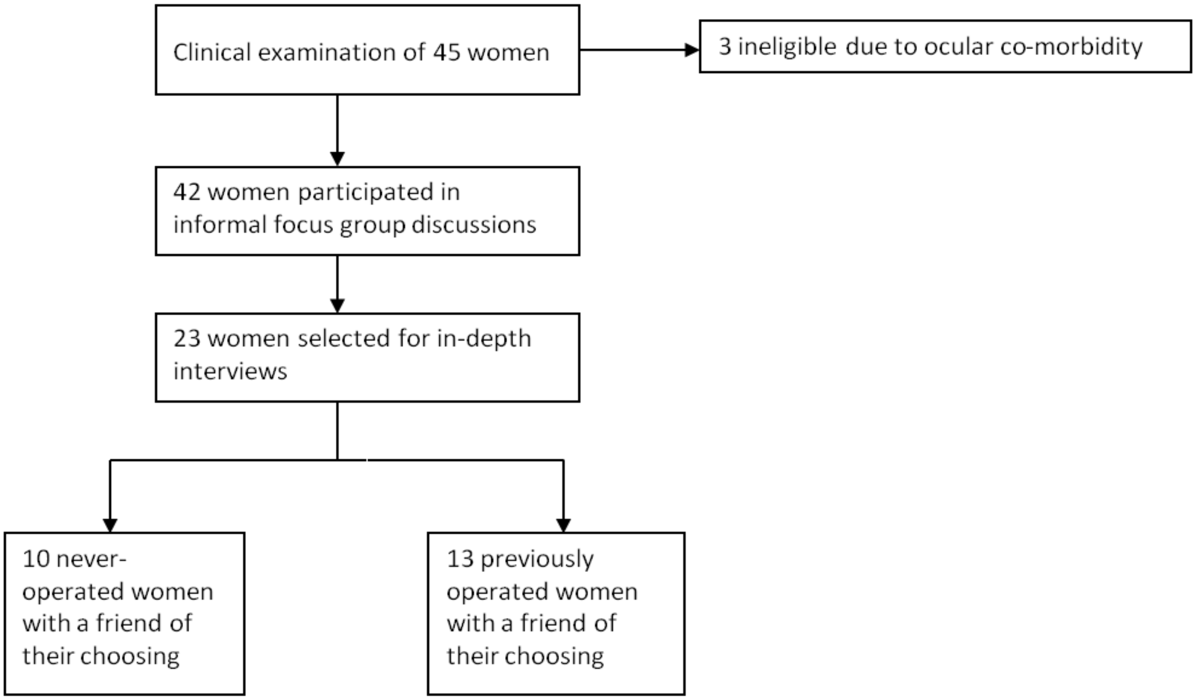


Table 1. Demographic and Clinical Characteristics of Operated and Unoperated Women (N=23).

Patient ID	District	Region	Age	Number of Times Operated	Time Since Most Recent Surgery	Bilateral Surgery	Severity of TT (Worst Eye)[1]	Currently Epilating (Either Eye)	Presence of Corneal Opacity (Either Eye)	Evidence of Post-Operative TT (Either/Both Operated Eye(s))
1	Zinder Commune	Zinder	70	1	6 months	No	None	No	No	No
2	Zinder Commune	Zinder	60	1	6 months	No	None	No	No	No
3	Zinder Commune	Zinder	50	2	3 months	Yes	Major	No	No	Yes
4	Zinder Commune	Zinder	80	2	3 years	Yes	Major	N/A	N/A	Yes
5	Zinder Commune	Zinder	35	0	N/A	N/A	Major	Yes	No	N/A
6	Magaria	Zinder	45	1	5 months	No	None	No	No	No
7	Magaria	Zinder	55	0	N/A	N/A	Mild	Yes	Yes	N/A
8	Magaria	Zinder	60	1	5 months	Yes	Major	Yes	No	Yes
9	Magaria	Zinder	30	0	N/A	N/A	Mild	No	No	N/A
10	Zinder Commune	Zinder	38	0	N/A	N/A	Major	Yes	No	N/A
11	Zinder Commune	Zinder	38	2	2 years	Yes	None	No	No	No
12	Zinder Commune	Zinder	30	1	6 years	No	None	No	No	No
13	Magaria	Zinder	25	0	N/A	N/A	Mild	No	No	N/A
14	Magaria	Zinder	35	0	N/A	N/A	Mild	Yes	No	N/A
15	Magaria	Zinder	70	2	6 months	Yes	Mild	No	No	Yes
16	Magaria	Zinder	35	0	N/A	N/A	Mild	Yes	No	N/A
17	Tessaoua	Maradi	40	0	N/A	N/A	Severe	Yes	Yes	N/A
18	Tessaoua	Maradi	27	0	N/A	N/A	Severe	Yes	No	N/A
19	Tessaoua	Maradi	90	1	25 years	No	Severe	No	No	Yes
20	Tessaoua	Maradi	20	2	3 months	Yes	Severe	No	No	Yes
21	Tessaoua	Maradi	50	1	3 months	Yes	None	No	Yes	No
22	Aguie	Maradi	40	1	10 years	No	Major	Yes	No	Yes
23	Aguie	Maradi	60	0	N/A	N/A	Severe	Yes	No	N/A

[1] None = 0 lashes or evidence of epilation
Mild = 1-4 lashes
Major = 5-10 lashes
Severe = >10 lashes

Community health workers also identified the heads of household for all of the trichiasis patients. In two villages, the minimum number of potential focus groups participants (six) could not be located at the time of the visit. A total of 26 heads of households participated in four separate focus group discussions, and focus group members ranged in age from 20 to 70 years. Each focus group had a heterogeneous make-up in terms of age and relationship to the patient. In some villages, the study team had difficulty finding the minimum number of participants required, so it was not possible to segregate focus groups by a particular characteristic. The average duration for each focus group was 50 minutes.

In most cases, responses given by operated and non-operated women were similar; therefore, the data presented below are aggregated unless otherwise noted. If additional themes or nuanced views were introduced by focus groups, these data are specifically indicated.

4.2 Definition of a Quality Life

All women stated that health, some specifically identifying eye health, was the most important indicator of a quality life. In addition, nearly all of the other indicators of a quality life were inextricably linked to health and to each other. Security was viewed as both a pre-requisite for and consequence of health. Security included having enough food for oneself and one's family in the present, as well as assurance of having enough to eat in the future. Women expressed this in terms of owning fields, granaries, and animals. Also included in security is financial security: having money "in one's hand" or having the means to make money or access it from family members when needed. However, in terms of relative importance, one patient's confidante stated: "If there are two people, one who is distributing money and the other who is distributing health, you would make a plea to the one distributing health" (Friend of Operated Woman, 70, Zinder Commune).

Security could be obtained in two ways: having the ability to provide for oneself and family through working, which necessitates having good health and the ability to move about, or as a member of a family and community. One patient stated, "…the husband, too, he needs to make money or find a way to make money. If not, there will be no peace; there will be no ideal life. If he doesn't have anything, you don't either" (Operated Woman, 60, Magaria). However, the importance of having a husband extended beyond gaining security; women described the partnership and personal relationship as important as well: "A good life, for example, is when you get along well with your husband, if you are together for better or worse. If you play and laugh peacefully with your husband and community, that's the good life for a person" (Operated Woman, 50, Zinder Commune). Children were also viewed as a source of security. In addition, they were an element of social standing within the community:

> …having children, it's an ideal life, because with time you grow old. If God gave you children, it's they who will help you to live, but if God didn't give you children, you won't be considered in the community. They'll talk about you everywhere saying, 'This old woman is bothering us.' But if you have children with money, even if you are handicapped, people will approach you and respect you (Unoperated Woman, 35, Zinder Commune).

Thus, factors of security were intertwined with another aspect of a quality life: social status. One's status in the community was gained and manifested through participation in reciprocal giving. This included giving money to help family members in need and distributing money during ceremonies, such as baptisms and weddings. Social status was also manifested not only through giving to others but also through the ability to borrow money:

> A quality life is when you have your health and you eat well. You have your health, you live well with your husband and other members of the family, you are able to do your commerce in neighboring villages or you borrow money from someone to increase your

> business. When you do that, you have your dignity and have money to spend in neighboring villages (Operated Woman, 38, Zinder Commune).

This ability to assist others was also a fulfillment of religious obligations[4]. Muslims are required to give a certain portion of their earnings to those less fortunate and are also taught to give additional charity as they are inspired or able: “I never killed a sheep for Tabaski[5], but I either killed or gave six live animals to family or neighbors who were needy” (Operated Woman, 90, Tessaoua).

4.2.1 Summary

In summary, then, a quality life was described as having health, security (alimentary and financial), living peacefully as part of a family and community, social standing and fulfillment of religious obligations.

4.3 The Effects of Trichiasis on Quality of Life

4.3.1 Physical symptoms

Participants described the severe eye pain of trichiasis: “I feel as if someone’s pricking my eyes with a thorn” (Unoperated Woman, 27, Tessaoua); “it is like someone pricked my eyes with a needle” (Operated Woman, 20, Tessaoua); or “it was as if it [my eye] was set on fire” (Operated Woman, 50, Tessaoua). Nearly all women described experiencing watery or purulent eyes and

---

[4] One of the five pillars of Islam is zakat, the mandatory donation of a percentage of one’s wealth and income to the poor. Sadaka is a voluntary act of giving, and includes giving alms or gifts during weddings, baptisms, or funerals.

[5] Tabaski (Eid al-Adha) is the Muslim holiday commemorating Abraham’s (Ibrahim’s) willingness to sacrifice his son Ismail, and due to his submission, God allowed him to sacrifice a lamb instead. It is customary for families to sacrifice an animal (generally a sheep) on this day and keep part to eat and distribute part of the animal to the poor.

problems with their vision: “I feel as if a veil is closing my eyes. It’s a sort of pus that sticks the eyes together. Someone has to open them for me” (Unoperated Woman, 25, Magaria). Itching and headaches were also commonly experienced. One woman said of the itching, “…it’s deep down in the eye that I feel the itching and I feel as if there are grains of sand circulating in the eye” (Unoperated Woman, 25, Magaria). Some women also reported experiencing swelling, fever, sores, photophobia, red eyes, and insomnia. No women reported experiencing no symptoms; however, some women reported only a couple of minor symptoms, while others reported experiencing many or severe symptoms. The number of symptoms or severity of symptoms experienced did not always correspond to the level of clinical severity of the disease.

4.3.2 Social relationships

The majority of patients had experienced social withdrawal and/or social exclusion: “…it [trichiasis] bothers me, especially with the tears and sometimes it prevents me from following my friends to participate in a village activity… if you don’t have eyes, it’s like a living death” (Operated Woman, 35, Magaria).

In other cases, the exclusion was imposed by others and sometimes based on the perception that a person with trichiasis is dirty: “It’s your group of friends who talk about you and put you down: ‘Look at this dirty woman. She spills her tears on everything she touches and cooks. Her hands and clothing are dirty’” (Operated Woman, 60, Magaria). The perception that a woman with trichiasis is dirty was manifested in her exclusion from sharing eye kohl with her friends, normally a mark of social acceptance, though in this case, may have protected her friends from infection. Another reason women were excluded from society was due to financial devastation caused by trichiasis. One patient's friend stated:

> When you have this illness, you have no money and you need to look for money. If you are sick, you need to go do certain work, like shelling millet, to have money to pay for medication. It's in this search for medication that her entire fortune was spent. And now, she has nothing. The difficulties that she's known, it's not something to joke about. And in this social life, they say if you have nothing, you are nothing (Friend of Operated Women, 70, Zinder Commune).

Several women stated that they had been made fun of by household and community members, albeit this was sometimes done in jest. They were called "one-eyed" or "blind." Other times, people would hold up their fingers in front of these women's faces, asking them to count the number of fingers they saw.

A few women spoke specifically about their relationships with men. All stated that their own husbands had treated them respectfully, although they had heard that other men abandoned their wives who had trichiasis or refused to eat dishes they had prepared due to the perception that she was dirty and her dish would also be dirty. However, one young woman stated that a man had come to ask her father for her hand in marriage but after hearing about her condition, he never returned. This incident was reiterated in one of the focus group discussions and the same woman's father lamented her inability to find a spouse when she had unoperated trichiasis.

4.3.3 Independence

The majority of women described ways in which trichiasis had affected their independence, though this was often cyclical and based around the management schedule of their trichiasis. Impediments to working were the biggest obstacle to patients' independence. Most stated that farming was difficult, if not impossible, and to a lesser extent, they encountered difficulties in housework and taking care of their children and animals. One woman's friend stated: "Cooking, other work such as going to the well, she couldn't do. Searching for wood, all that she couldn't do. Everything, even water and wood, she had to buy. She had to buy everything because of trichiasis" (Friend of Operated Woman, 70, Magaria).

Many women also stated that they had difficulties in their mobility, which was a cause of severe distress: "I had twelve children of which six are dead and six are living. But at that time, I lacked nothing in my life, thank God, until the illness attacked me and stopped me from being able to get around" (Operated Woman, 90, Tessaoua). Focus group participants confirmed patients' immobility, and also added that the inability to move around freely also impeded their ability to practice their religion as they wished, since they were unable to walk to the mosque for Friday prayers.

A few women also talked about losing their financial independence: "What became of my life? What could I do? I didn't do anything. Before, I used to do my commerce, but after, I couldn't. I cooked donuts and it [the smoke] closed my eyes" (Operated Woman, 38, Zinder Commune). One friend describes a patient's complete lack of ability to provide financially for herself: "If she cultivates, she'll kill the millet. What difficulty is bigger than that? She doesn't cultivate. In order to eat, she has to beg. She has no one who will bring her something to eat. This trichiasis, that's the difficulty" (Friend of Unoperated Woman, 60, Aguié).

4.3.4 Family Burden

Trichiasis was a cause of burden on the family of patients. For example, in Niger, children often share in the household work; however, one patient's mother recalled,

> I didn't even make her work. I saw children go to the well, but me, I didn't send her. When I saw her eyes, I told myself, 'I won't make her do any work. She won't do any work for me. Even to go sell something, I won't send her' (Friend of Operated Woman, 20, Tessaoua).

After a woman is married, she becomes part of her husband's family, and it is up to his family to take care of her. One unoperated patient stated that during a period of illness, her own mother had to take the unusual step of coming to care for her.

Men in households with trichiasis patients were affected in two main ways. First, since women were often unable to perform household and farm work to support the well-being of their families, at times, it was men who took over these duties. One woman said that it was her husband who did the cooking and laundry in the household; this was validated by male focus group members who stated that they had had to cook, clean or perform other domestic chores when women were ill. As one focus group indicated, these duties are almost exclusively performed by women and girls in the domestic setting in Niger, and a man doing these duties may be made fun of or lose respect unless doing them as paid employment. Second, men were affected financially. Many of the focus group discussions revolved around products purchased to help ease patients' pain, as well as specific sums of money that had been spent in search of a cure for them.

4.3.5 Pre-Surgical Management of Trichiasis

Patients described living with trichiasis as a constant, often futile, search for a cure. The mother of one operated woman, who had been afflicted with trichiasis from a young age, stated "Everywhere where I heard there was someone with medication, I would go. Like that, I did everything. But nothing [helped]" (Friend of Operated Woman, 20, Tessaoua).

Nearly all operated women spoke about ways in which they managed their trichiasis prior to surgery, and most non-operated cases spoke about their current practices or their knowledge of what other patients do. These practices included visiting traditional healers, applying traditional topical medications, cutting off the eyelashes with scissors, and epilation, which was cited most frequently. The few unoperated patients who did not have coping strategies had mild trichiasis, and one had received a diagnosis of trichiasis during the clinical examination prior to the interview. Several other unoperated women practiced epilation regularly, but only one had ever presented for surgery. A health worker had said her trichiasis was not yet "ripe." At that that time, she reported that her trichiasis did not bother her yet; however, her condition had since progressed and now required her to epilate for pain relief.

The relief patients obtained through these strategies was described as cyclical: most patients would experience the pain and other symptoms of trichiasis, epilate, and then the cycle would generally repeat every couple of days ("Today I am epilated, tomorrow I am epilated" (Operated

Woman, 38, Zinder Commune)). In general, operated patients viewed epilation as a way to provide immediate pain relief, while surgery was a long-term cure:

> And then they were searching for an instrument to epilate me, and they heard there was this operation, and I said 'I'm going to go do it'. . . This surgery is better … yes it's superior to the other [epilation], but since they operated me, there have been no others [trichiatic lashes] (Operated Woman, 70, Zinder Commune).

Several operated and non-operated women and their confidantes spoke about the need to find someone who knows how to epilate correctly, referring to a belief that trichiatic lashes are different from one's "real" eyelashes that should not be pulled out, and that someone lacking appropriate knowledge may epilate the "real" lashes. This belief is attributable in part to the fact that trichiatic lashes may be different in texture from non-trichiatic lashes. Once a patient found someone with the knowledge to epilate (generally a family member), she would have to offer payment for the service (money or cola nuts). One unoperated patient suffered a degree of humiliation when she needed to be epilated: "Sometimes she [the epilator] tells me, 'Me, I am tired of epilating your eyelashes.' I wait patiently or leave, but that doesn't stop me from returning. After two days, I come back . . . I have to beg her" (Unoperated Woman, 27, Tessaoua). Due to these difficulties with epilation, free surgery was viewed as a welcome alternative. One confidante stated, "You needed to call someone to epilate you, during the time of ignorance, and you needed to pay, but now they do operations free at the hospital, so when you start to feel the trichiasis, you will not hesitate" (Friend of Operated Patient, 50, Zinder Commune).

Non-surgical trichiasis management strategies were also seen as detrimental to the health of the eye by operated patients: “If you are healed, it’s over, but if you cut the lashes today, tomorrow, after tomorrow, the illness will go and attack the eyes. At the end, you will completely lose your sight; you will have no more life” (Operated Woman, 60, Zinder Commune). However, no unoperated women expressed this viewpoint.

Illness, including trichiasis, was viewed by those who had been operated as a disruption to a quality life. Epilation was seen as part of the state of illness and was therefore not considered compatible with a life of quality:

> And whenever it [trichiasis] stings you, you feel pain all over your head. It affects your spirit, so one can’t speak of a life of quality with this pain you feel. Sometimes when it bothers you, you need to epilate in order to feel relief. When I had trichiasis, I always had my tool with me to epilate with. Before the trichiasis developed, at this time, you felt better and you could say that you had an ideal life (Operated Woman, 80, Zinder Commune).

All focus groups spoke about the trichiasis management techniques mentioned above, including their own search for and purchase of whatever source of relief they could find for their family members. The practice of epilation was described as “ignorant” by one focus group. A second focus group stated that epilation was viewed unfavorably due to a belief that trichiasis can be transmitted through epilation.

4.3.6 Summary

Trichiasis caused many impediments to a life of quality, both for the women themselves and their families. The effects included:

- Poor health, manifested through pain, watery/purulent eyes, fever, sores, photophobia, red eyes, and insomnia;
- Social withdrawal and exclusion, which were manifestations of stigma and loss of social status;
- Loss of independence, including inability to work, difficulties in mobility, and loss of financial independence;
- A feeling that they were a burden on their families: making extra work for other family members, causing financial burden, and requiring men to perform “women’s work”;
- The need for constant management of their condition through epilation or other means.

4.4 Perceptions of Trichiasis Surgery and its Impact on Quality of Life

All but one operated patient stated that trichiasis surgery had improved their quality of life, and the one patient whose life had not been improved stated that she would still repeat the surgery to rid herself of the pain. For nearly all of the patients who had undergone surgery, the improvement in quality of life was expressed as an amelioration or complete disappearance of physical symptoms. Both operated and unoperated women and focus groups participants viewed trichiasis surgery as a life-changing experience: not only was health regained after surgery, but life was as well. One woman stated, “All who received the surgery are healed. There are no more tears in the eyes or eyelashes that prick. They have recovered their best life” (Unoperated Woman, 38, Zinder Commune).

In nearly all cases, patients regained independence, including their abilities to work, conduct small business enterprise, and move around. One patient stated: “When they did this to us [operate], we came back and were able to go about our work. You see, this brought us many advantages” (Operated Woman, 70, Magaria). Her confidante added, “This surgery brought them many advantages. Truly, they felt an improvement in their quality of life. You do your work, you cook … You didn’t even have money; someone with good will needed to help you.”

Increased independence allowed women to re-integrate socially. There was no indication that social problems encountered during the period of illness persisted after the surgery, and patients were able to resume their relationships and activities. The head of household whose daughter had trouble finding a husband stated,

> The person who was operated will recover her good life in relation to the person who was not operated. My daughter, before the operation, couldn’t do anything. She couldn’t move about and boys didn’t want to flirt with her, but now she is married. Truly, I have seen its advantage (Focus Group 4, Aguié).

One operated woman stated,

> My expectations [of surgery] were to recover my health: see where I want with my eyes; look after my husband; be able to do my work, cooking, farming; travel and go where I want and be able to integrate into the community without difficulties … My expectations were satisfied and my vision has improved (Operated Woman, 30, Zinder Commune).

4.4.1 Surgical Expectations and Outcomes

Nearly all operated patients expected to improve their health through trichiasis surgery, while a few also explicitly stated that they had hoped to regain their abilities to work, travel and re-integrate socially. Almost all operated patients stated that their expectations were fulfilled through surgery, though several women had to have more than one surgery before their trichiasis was corrected. In most cases, they expressed satisfaction that their symptoms, such as pain and watery eyes, decreased or disappeared and their vision improved. Additionally, women expressed pleasure about regaining their abilities to work, travel, and to take part in social activities again. One operated patient's confidante stated, "Since the operation, she hasn't sat down" (Friend of Operated Woman, 40, Aguié).

Paradoxically, all but one patient whose surgery had been unsuccessful and had post-operative trichiasis (including major and severe cases) stated that their surgery had been successful. One woman with severe post-operative trichiasis (>10 lashes touching the eye) stated, "Since I had the operation, I never felt anything bad in my eyes" (Operated Woman, 27, Tessaoua). Only one patient said that she had experienced no improvement from the surgery, and was, in fact, in a worse state: "If I had known what was to come, I wouldn't have gone. I would have been happy with my initial situation which didn't stop me from working" (Operated Woman, 50, Tessaoua). However, despite her poor outcome, this patient recognized that others had had successful outcomes. Later in the interview, this woman even stated that she would be willing to undergo surgery again in the hopes of improvement.

4.4.2 Surgical Complications and Recurrence

While surgery itself was viewed positively and improved quality of life, women, especially those who had been operated, were also aware of the risk of complications following surgery and recurrence of the disease. Just under half of the operated patients spoke about the possibility of complications or recurrence, but only one unoperated patient did. Among the operated patients, all believed that any problems resulting from surgery were caused by not following instructions given for post-surgical care:

> The problem, when someone tells you to do this or that thing, you need to respect what they tell you and you'll see no problem. Everyone you see who was operated is told, 'here's what you need to do; you must do this.' If you didn't respect it, if you make a mistake, it's you who wanted it (Operated Woman, 70, Zinder Commune).

4.4.3 Convalescence and Post-operative Care

About half of the operated patients spoke about their convalescence period, with one woman reporting that she took no time to heal before she began her activities, while another woman had not re-started her work at the time of the interview, six months after the intervention. Of those who spoke about convalescence periods prescribed by their surgeons, most stated that they were told to rest for approximately three weeks. None of the operated patients thought that the time required to convalesce was too long; contrarily, many of them expressed their willingness to rest however long was needed to be healthy: "I didn't work … I sat for three months, but if they told me to continue, I would do it with joy. It's me searching to recover my eye health, I must follow the instructions" (Operated Woman, 60, Zinder Commune).

Approximately half of the unoperated patients also spoke about what they had heard or observed regarding the convalescence period, and the majority reported that patients spent approximately three weeks in recovery. However, all but one of the unoperated patients believed this time period was too long. One young woman thought that the only manageable way for her to take this amount of time to recover would be during her next "*quarantaine*"[6]:

> You know, if a person gives birth, during the *quarantaine*, she doesn't work. After the surgery, they [surgeons] give medication that she can use for these forty days, so she won't have to do the washing and she can attend to her operated eyes and to her baby. For example, even your husband, when you are in the *quarantaine*, you haven't anything to do with this work. In this situation, you can rest until you have healed (Unoperated Woman, 27, Tessaoua).

One other unoperated woman stated that she was the head of her household and had no one else to take care of her children, so an extended recovery period would be difficult, if not impossible.

Following surgery, all operated patients were given some instructions of what to do to promote the healing process, though instructions varied. A couple of patients were simply given some topical tetracycline eye ointment (TEO) and told to apply it to the surgical site; several others were given TEO, azithromycin, and soap, as well as instructions on how and when to wash their faces and apply the TEO. About half of the patients were told to avoid all work or travel. Only a few patients talked about being told to return to the health center. Of those who did, a couple were told to come back after three days to have their bandages removed; one was told to return

---

[6] The "quarantaine," which translates literally to "the forty" refers to a cultural practice during the forty days after giving birth when a woman does not leave the home so that she can take care of her infant and heal. During this time period, the woman does not perform any work or engage in conjugal relations. In addition, there are prescriptive cleansings she must adhere to that are believed to promote healing. At the end of the forty days, the woman performs a ritual cleansing and begins to pray and resume her other normal activities.

one week post-surgery to have the sutures removed. Only two unoperated patients spoke about post-operative care; they were aware that patients were not supposed to work.

4.4.4 Summary

In all but one case, operated women reported that trichiasis surgery had improved their quality of life, and unoperated patients generally believed that the surgery had improved the quality of life of those operated. In particular, the surgery was reported to:

- Alleviate pain completely or at least to a manageable level;
- Allow women to regain independence;
- Enable women to re-integrate socially.

Women expressed satisfaction with a wide array of postoperative clinical outcomes but worried about the possibility of recurrence and tended to blame themselves for complications.

4.5 Decision-Making and Factors Influencing the Decision to Undergo Trichiasis Surgery

In almost every case, the decision to be operated involved no forethought or pre-planning. Instead, the decision was made on the spot when a surgical team arrived in a village to diagnose and transport patients to surgical camps:

> The children saw the car and cried out, ‘the trichiasis surgery car is here, the trichiasis surgery car is here!’ At the time, I was working but I said, ‘I’m going to go see,’ and I freshened up and left. After looking at my eyes, he [the surgeon] told me there was trichiasis in my eyes, and I accepted to be operated (Operated Woman, 50, Zinder Commune).

The majority of operated women stated, at times insistently, they had made their own decision to be operated, though many stated that while they had made their own decision, they still informed their husbands, co-wives, brothers, or other family members, who then accepted the patient's choice:

> I didn't have time to ask, as soon as I heard of the arrival of the team, I ran, and when I arrived, I asked them to examine me too, and as soon as she [the surgeon] saw me, she told me, 'You see, you have swollen eyes, I don't even need to look. You have trichiasis.' And I said I had to go tell the house, so I found my husband and told him that there were many of us and I was lucky to be chosen. He told me to go ahead and get operated (Operated Woman, 60, Zinder Commune).

In another case the woman stated that she made her own decision to be operated at the hospital in the district capital; however, she did not have the means to pay for it and needed her husband's approval in order to obtain the necessary funds. In a few cases, other family members, such as women's children or husband, made the decision on behalf of the patient, who then accepted their decision.

Several unoperated patients also suggested that the decision not to be operated was made not by themselves, but by a health agent. One patient, when asked by the interviewer if she wanted to be operated, stated, "Of course. Whatever the distance I would have to travel, even if I didn't have the means for transport, I would go, because I'd like to recover my eye health, if really you [referring to the interviewer whom she thought was a health agent] think it's time for me to be operated" (Unoperated Woman, 35, Zinder Commune). When the interviewer pressed her as to why she had not been operated when previously diagnosed, she said, “He [the surgeon] said that for me, it’s very little, it can’t be operated, and I said ok. Since then, even if I heard about a trichiasis surgical team, I didn’t present” (Unoperated Woman, 35, Zinder Commune).

In terms of general household decision-making, some women stated that while a woman can make a decision, she can only act on this decision when given permission by her husband. However, even in cases where the woman talked about the authority of her husband to accept or refuse a decision, all of the operated patients stated that women have the right to participate in the decision-making process, propose ideas, and give their opinions. Focus groups also agreed that women could make decisions or could be involved in the household decision-making process, though the head of household still held the authority to permit or refuse. However, one basis for this authority was control over household wealth or having personal income: men stated that women needed to obtain permission from their husbands because women would need money to carry out what they wanted to do; women stated that when they had money, they were consulted about household decisions.

4.5.1 Disadvantages of and Barriers to Surgery

Participants were asked what they felt were disadvantages to the surgery and what might keep those who had not yet benefited from surgery from accessing it. Several of the operated patients could not identify any reasons why someone who needed surgery would not access it, and some of the unoperated patients also insisted that there were no drawbacks to the surgery. One patient’s friend stated: “You see, we go to the clinic there if the illness has cornered us, nothing can stop you because health, that's it. Health has chased away everything, it's health who is ahead of everything" (Friend of Operated Patient, 70, Magaria).

A few women spoke about the pain of receiving the anesthetic and the surgery, and several women also mentioned the possibility of having an unsuccessful surgery or of complications from the surgery as concerns that may prevent patients from accessing the surgical service.

4.5.1.1 Caretaker

The majority of women recognized the necessity of a caretaker after surgery. For certain, this did not seem to be a barrier, as they had co-wives, children, or close friends who were able and willing to assist. One confidante stated: "For example, if one of us is sick, the other will take responsibility of caring for her (Friend of Unoperated Woman, 35, Magaria)." However, some operated patients and focus groups recognized the lack of a caretaker could be a barrier for others, especially during the rainy season, the time of heavy agricultural work:

> During the rainy season, people don't accept easily. The difficulty is that someone is alone at her house, she doesn't have help, and she has children and work. Sometimes there's no food because the millet isn't ready to harvest; sometimes she can't even find millet to buy. That's why it's hard to be operated. During the dry season, you've already harvested. A relative can stay and cook for your husband and children, but now, during the rainy season, not everyone is able to be operated (Friend of Operated Woman, 70, Magaria).

However, for some of the unoperated women, the lack of a caretaker was reported to be a barrier throughout the year. One woman, a single head of household, had small children at home and no adult relatives able or willing to care for her. She was responsible for all the household work. She also lacked the additional security of a granary with millet or animals that could be killed to eat, so she was forced to go out every day and look for food for her family, which she would not be able to do during convalescence.

4.5.1.2 Healthcare Workers and Lack of Information

None of the operated patients identified healthcare workers or inaccurate information as potential barriers to surgery; however, several of the unoperated patients had not been operated specifically because of healthcare workers: a couple of patients had been told by surgical teams that their trichiasis was not yet ready for surgery: “You see, I was the only trichiasis patient who was not operated last year. I was examined by the intervention team but they told me that the trichiasis was not yet ripe” (Unoperated Woman, 35, Zinder Commune) Another had been told that there was a “list” of names for each surgical camp opportunity, and her name had not yet appeared on one of these lists. A couple of the unoperated women also stated that while they were aware of surgery in their area, they had not received the information on time or a referral to present.

Several of the women had never been diagnosed or had been misdiagnosed. One unoperated patient stated: “I didn’t know that it was trichiasis in my eyes, that why I haven’t forced myself to seek out the surgery. And then, when I came, when I did go, they looked at me and told me there wasn’t any, so I continued my work” (Unoperated Woman, 25, Magaria). In this specific case, a woman with minor trichiasis, it is possible that at the time she presented, she may not have yet developed trichiasis. There was another patient who had been diagnosed but then doubted the diagnosis, as she had never had to undergo epilation, a practice presumed to indicate the presence of trichiasis.

4.5.1.3 Fear

Focus groups and a few of the operated patients focused on fear and ignorance as reasons other patients had not accessed surgery, though none of the unoperated patients stated that fear had factored into their failure to access surgical services. All of the operated patients insisted that they had not been afraid of the operation: “I told myself that even if it’s to die, I will not be afraid” (Operated Woman, 40, Aguié). Another woman who had previously had poor outcomes following surgery was asked by the interviewer if she would be afraid to undergo another surgery due to her previous experiences, and she responded, “I’m looking for health. Even right now I could accept the intervention. I don’t fear anything; I am looking to get rid of this pain” (Unoperated Woman, 50, Tessaoua). However, several of the operated patients did state that they knew of patients who had presented for surgery but then left before being operated: “They are afraid, they all came and left before the examination. There was one who was on the examination bench and she soon fled” (Operated Woman, 60, Zinder Commune). This last comment was in relation to a woman who had initially shown up at the study site but then fled before being screened. In addition, patients did express concerns about surgical failure or poor outcomes, which may be the source of fear for some patients.

4.5.2 Summary

In general, women were able to make their own decisions to be operated with little pre-planning. However, if the decision required money, they would either have to have their own means or would need to seek permission (and funds) from their husbands or other family members. In some cases, health agents made the decision, by telling women their trichiasis was not yet “ripe” and not operating them. Despite efforts by the PNLCC, some barriers still keep women from accessing surgery, including:

- Fear of unsuccessful surgery or complications from the surgery;
- Lack of a post-operative caretaker;
- Misinformation from surgeons, such as telling patients their trichiasis was not yet ready to be operated or misdiagnosing patients and telling them they did not have trichiasis;
- Lack of information about time/place of the surgery or misinformation about “lists” with names of the patients to be operated during a given surgical camp.

5.0 Discussion

5.1 The Effects of Trichiasis on Quality of Life

Trichiasis profoundly affects the quality of life of many with the disease, even some presenting with clinically mild trichiasis. For many, the pain is intense or unbearable and described as a thorn or needle pricking the eye or feeling as if the eye was set on fire. For some, the embarrassment of others seeing their purulent, watery eyes kept them shut in their homes and isolated from the wider community, which was described as "a living death." Others desired to be socially active but were stigmatized and mocked by family, friends and neighbors. Trichiasis was reported to affect women's mobility, ability to work, and ability to earn an income, thus rendering them dependent on their families and potentially decreasing their influence in family decision-making. It also prevented women from engaging in financial reciprocity, either lending or borrowing money, and their ability to give alms to fulfill religious obligations thus lowering their social status. The effects of the disease also extended to the entire family and caused social and financial burden, as well as extra work, on other family members. These findings are consistent with and add to understanding gained from anecdotal sources (The Carter Center, 2009).

The findings on loss of independence (specifically, inability to work or move about) are also consistent with the findings of Dhaliwal et al.'s case-control study in India (2006), Frick et al.'s study on trichiasis and disability in Tanzania (2001); and Wolle et al.'s study in Ethiopia (2011). These studies all conclude that trichiasis in the absence of vision loss is a cause of physical disability, and Frick et al. (2001) postulates that the effect is greater among women. Dhaliwal et al. also show that trichiasis patients have poorer psychological health and a poorer environment than controls (cataract and refractive error). However, Dhaliwal et al. were unable to show any differences in social relationships between cases and controls. In the present study, many of the women reported incidents where they were mocked, excluded from participation in social activities and withdraw themselves from the community because of fear of stigmatization. It may be that women do not view their disease as causing a change in the relationship itself, or these incidents may have been internalized and be reflected in the poorer scores on psychological health and not in the social relationship category.

5.1.1 Loss of Independence

Frick et al.'s Tanzanian study (2001) found that among women, trichiasis alone, even in the absence of any visual acuity loss, causes difficulties in performing daily tasks, and loss of visual acuity compounded these difficulties, which is supported by the present study. The inability to move about and work affects every other aspect of these women's and their families' lives. Women are important contributors to fieldwork and are the primary contributors to housework and childcare (UNICEF, 2006). Many of the women in the present study were involved with microenterprise and had either had to stop or decrease their activities when they developed trichiasis. There is evidence that women and men use their earnings differently, and that women are more likely than men to invest their income in goods and services that improve the well-being of the entire family (Duflo, 2012); therefore, when a women becomes too disabled to work, all family members may be negatively affected. In addition to decreased income, there is increased financial output, as wood, water, food, which the woman would normally collect or grow herself, may need to be purchased. In addition, there is increased spending on treatments to alleviate the pain of the disease.

This decreased or absent income may also diminish a woman's influence within the home. While many of the operated women stated that they had made their own decisions to be operated, this was generally in the context of free surgical service provision and transportation to and from the surgical camp site. Broader discussions with both patients and male heads of households around household decision-making revealed that women were involved in the decision-making process when they could contribute financially. When women no longer have a meaningful income, they may no longer be consulted about household affairs.

5.1.2 Reciprocity

As stated above, a woman with trichiasis was often disabled by her condition. This in turn made her a burden on other family members and also limited her ability to give to others during baptisms, marriages and funerals. In *The Gift*, sociologist and anthropologist Marcel Mauss argues that this giving is not altruistic and is instead a social contract. Giving results in increased social status for the giver and creates an obligation of reciprocation for the recipient (1925). Neglect or inability to return the favor will result in a loss of social status (Mauss, 1925). This phenomenon is illustrated by one woman's words, "If you don't have money, you can't do anything and no one tells you anything. They'll say that someone who doesn't have anything, he doesn't live, so how will he help someone else live? (Operated Woman, 70, Zinder Commune). In such a precarious environment as Niger's, keeping this social code may be analogous to survival.

5.1.3 Stigma

Social exclusion and self-isolation are both markers of stigma, the former indicating that one is actively being stigmatized and the latter, that one fears being stigmatized or has internalized the stigma. Many of the women with trichiasis spoke about ways in which they had been stigmatized: being called names; being excluded from participating in activities, such as sharing a plate of food or eye kohl; needing to travel to a different village to be epilated; and being considered worthless as a marriage partner. This is contrary to Dhaliwal et al.'s study in India (2006), which stated that trichiasis did not make trichiasis patients social outcasts and there was no social stigma attached to it. In the present study, some women did not report being the object of stigma, and in cases where they had been, there were no reports of remaining stigmatized after surgery. It is unclear whether this is tied to the severity of the disease, the social status of the woman, or other factors. Trichiasis may be viewed differently in India than in Niger; alternately, the instrument did not ask the correct questions to elicit this information.

Epidemiological research has demonstrated that decreased social integration can have deleterious effects on health. One of the best documented effects is increased risk of mortality. A review of the relationship between social integration and health illustrates that a number of studies in a variety of settings have shown that the relationship between decreased integration and increased mortality are independent of other measures of health status and socioeconomic status (Seeman, 1996). Many studies have also shown that increased social integration has a protective effect against mental health problems, such as depression and psychological distress (Moen, Dempster-McClain, & Williams, 1989).

Social integration has also been shown to indirectly affect health as well. First, integration fosters positive self-esteem, which leads to increased health. Second, it can influence health behavior, including treatment seeking, and increases access to health-related resources. Finally, having social ties can lead to increased support in times of need (Moen, et al., 1989). One of the main barriers to surgery identified in this study was the lack of a caretaker following surgery. Women experiencing this barrier may not be as well connected and may become even less so when they are not able to go about their normal activities as a result of trichiasis. This lack of integration may also prevent women with trichiasis from hearing about surgical services, as an unpublished study in three countries, including Niger, indicated that 47% of unoperated men and women with trichiasis receive general health information from their friends and neighbors, and 34% of those who had heard about trichiasis surgical services had heard about them from a friend (Palmer et al., 2012). This stigma, leading to social exclusion and self-isolation, and the subsequent lack of information and resources, is what these women are referring to when they call trichiasis "a living death."

5.1.4 Effects on Men

Women's inability to perform fieldwork and domestic chores also created a burden on other family members, including men. Focus group participants discussed their role in assuming responsibility for cooking and sweeping when their wives and mothers were ill, and one patient also stated that her husband cooked and did laundry. However, no literature reporting this behavior could be located, so it is unknown whether these are isolated or common incidents; whether it is specific to the disease of trachoma or illness in general; and whether this is specific to rural Niger or occurs elsewhere in trachoma-endemic settings.

5.1.5 Epilation

Before undergoing surgery, many patients managed their trichiasis through epilation or other strategies. Previous studies in Ethiopia, The Gambia and Tanzania have shown that only about one-quarter to one-half of patients uptake surgery, even when it is offered free of charge (Rajak et al., 2011b). One plausible explanation for this is that patients are content with their current management practice (Rajak, Collin, & Burton, 2012). Indeed, in a non-inferiority trial in Ethiopia examining outcomes of surgery versus epilation, patients were randomly assigned to received trichiasis surgery or receive high quality forceps for epilation along with training on how to epilate. Following this study, all patients in the epilation group were offered free surgery and only 31% consented, yielding the explanation that patients preferred to continue epilating (Rajak et al., 2011b).

In the current study, the majority of operated and unoperated patients spoke about management practices, and both groups viewed surgery as preferable to epilation or other practices. While epilation provided pain relief, it was viewed by participants as part of the state of illness and incompatible with a quality life. However, it is possible that there may have been some degree of reporting bias, with participants perhaps believing that not reporting a preference for surgery may prevent surgical teams from returning to the area. If National Programs are considering offering epilation as an alternative to surgery, then formative research should be conducted to determine patient acceptance of the practice.

5.2 Trichiasis Surgery and Effects on Quality of Life

Surgery was viewed very positively by both operated and nonoperated patients and was reported to improve overall quality of life, including health, the ability to work and move around, and a return to social activities, although a few patients reported requiring more than one surgery in order for their quality of life to improve. Of concern, however, is that patients reported satisfaction with poor clinical outcomes. This is consistent with an unpublished study conducted in Niger, which showed that 90% of operated patients reported that their overall condition improved after surgery and 97% reported that their pain had been reduced or disappeared, despite 30% recurrence (Palmer et al., 2012). In studies looking at satisfaction with cataract surgery, patient satisfaction was not only related to an improved clinical state, such as improved visual acuity. These studies also linked postoperative patient satisfaction with pre-operative expectations (i.e. low pre-operative expectations yield higher post-surgical satisfaction), as well as with perceived quality of care (Nijkamp, 1975). In the present study, most patients articulated their pre-surgical expectations in terms of regaining their vision, and many of the patients reported improvements in vision, as well as gains in independence and social integration, though we were not able to substantiate this by comparing pre- and post-surgical visual acuity. The patients spoke positively about the surgeons themselves, the counseling provided, and the medication and soap distributed.

While the primary goal of trichiasis surgery is not aesthetic improvement, it may improve the physical appearance of the eyes by rotating the eyelid margin so eyelashes are correctly displayed. It also alleviates the excretion of tears and pus from the eyes. A previous unpublished study demonstrated that the majority of patients in Niger (95.3%) reported that the appearance of their eyelids improved after trichiasis surgery (Palmer et al., 2012). Studies in the field of aesthetic surgery have shown that among patients dissatisfied with the appearance of a body feature, those who had the surgery expressed more satisfaction with their appearance than those who did not undergo surgery at one year of follow-up. Those who had surgery also had higher scores on measures of well-being (self-esteem), quality of life (health status, disability) and psychopathology (anxiety, depression and social phobias) than those who had not undergone the surgery (Margraf, Meyer, & Lavallee, 2013).

Another explanation is that when patients report satisfaction despite having postoperative trichiasis, their clinical pictures actually may have significantly improved. This study did not collect pre-surgical clinical information, so we were unable to compare. Finally, some patients who are not satisfied with the outcome of their surgery may be afraid to speak frankly, fearing that their testimony could offend those offering the services and/or resulting in the cancellation of future health services.

5.2.1 Barriers to Surgery

Despite the overall positive reports, there are still some barriers that keep patients from being operated. Barriers to accessing surgery identified by previous studies include cost, time, fear, lack of information about time and place of surgery, lack of transportation, mild symptoms and lack of an escort to the surgery as barriers to accessing surgery (Bowman et al., 2002; Rabiu & Abiose, 2001; Rajak et al., 2012). Several of these barriers (time, lack of information, fear, and mild symptoms) were identified by participants in the current study. For participants in this study, time appeared to be an obstacle to surgery in two different scenarios. First, it was reported to be a barrier if the surgery was being held during the rainy season, which is when all able-bodied individuals also need to be in the field working. Second, the amount of convalescence time was a barrier for women who had no one to assist them at home, especially if they had small children.

Some unoperated women identified lack of information about services as an obstacle which led them to missing out on opportunities to be operated. However, in most cases, a lack of foreknowledge of the surgery did not appear to keep patients from undergoing surgery; rather, women found out about the surgery when the surgical team arrived in the village and the decision to be operated was made at that time. Lack of information was also an obstacle if patients had never been diagnosed with trichiasis and therefore did not know to present at surgical opportunities.

Health workers may act as barriers or facilitators for surgery, as they diagnose the disease and declare it ready to operate or not. It should be noted that all cases of trichiasis are considered operable (International Coalition for Trachoma Control, 2012), and education can help make both patients and surgeons aware of this. In most cases, patients tended not to question directives given by healthcare workers, whether it was concerning the necessity of surgery or the post-surgical instructions they needed to follow. Thus, when surgeons tell patients that their trichiasis is not “ripe” for surgery, patients may not question this and may not re-present at another opportunity, despite increased risk of blindness. While surgeons may select only severe cases of trichiasis to operate if time or consumables are limited, this may de-motivate patients and allow further disease progression. This can be avoided by better program planning, or by offering alternatives to surgery, such as epilation if it is acceptable to patients, until the surgical team can return.

Finally, fear was addressed only briefly by participants. No operated participant said that she had been afraid prior to surgery, though a couple gave examples of people they knew who had been afraid; none of the unoperated patients mentioned fear. However, fear was one of the primary barriers cited by focus group participants. Unoperated patients may be unwilling to cite fear as a barrier, for fear of being mocked, and those who have undergone surgery or not do not have the disease may not recognize the actual constraints that are keeping patients from accessing surgery.

Three of the frequently identified barriers in previous studies, cost, lack of transportation and lack of someone to accompany the patient to the surgical site appear to not be obstacles in rural Niger. This is most likely due to most surgery and transportation being provided free of charge.

One barrier that has not previously been published is the lack of a caretaker for patients after surgery. The lack of a caretaker appeared to be the only barrier for two otherwise motivated women. Women who are heads of households or who do not have co-wives, daughters-in-law, older daughters or strong social networks may find it especially difficult to overcome this barrier.

5.3 Study Strengths

To our knowledge, this is the first qualitative study looking specifically and systematically at quality of life among women with trichiasis, in addition to the decision-making process for trichiasis surgery. Using qualitative methods to answer questions that are, by nature, qualitative questions elicits greater information than would a standardized questionnaire. This study was also able to provide additional insight into reasons why trichiasis patients do not present for surgery.

The rich description of living life with trichiasis and how surgery improves these women's lives serves as a call to action to Ministries of Health to prioritize trachoma control programs; to implementing organizations to continue to support this important work; and to donor agencies to fund the implementation of the SAFE strategy to eliminate blinding trachoma in endemic countries. Many organizations use standardized measures such as DALYs to set priorities for the funding of disease programs. However, these measures vastly underestimate the burden of trachoma, as they do not capture the disability resulting from trichiasis in the absence of visual impairment or blindness. DALYs are also unable to capture the stigma or family burden caused by this disease. In addition, these measures do not take into account the emotional or financial burden on families and communities or acknowledge the fact that not addressing diseases that primarily affect the poorest of the poor can actually lead to greater inequities in terms of health status and poverty (Hotez & Kamath, 2009).

This study was able to capture detail about living with trichiasis not previously described, address several aspects of the experience of trichiasis that had not previously mentioned, and identify barriers to accessing surgery not previously reported in the literature. In addition, it adds to the understanding of patients' perceptions of epilation or women's role in decision-making for trichiasis surgery. We were unable to locate any literature on men taking on household tasks traditionally performed by women. These aspects provide a more nuanced view of the disease and its effects on patients and families.

In addition, we use the relatively uncommon methodology of interviewing women pairs. While we used this method primarily to provide moral support for the women being interviewed, we discovered some added benefits. First, the friends often comprehended the meaning of the questions before the patients and were able to explain what the interviewer was asking. Second, the method added legitimacy to the study team in the eyes of the villagers, as asking lone women to be interviewed in a private location by an unknown man may have aroused suspicion. Finally, some of the friends selected by patients, while not selected as primary interviewees by the study team, had also been trichiasis patients, and were able to share some of their experiences, which enriched the data.

5.4 Study Limitations

This study was undertaken in order to collect rich detail on how trichiasis affects the quality of life of women with the condition in rural Niger. The understanding gained from these women cannot be generalized to urban women with trichiasis in Niger, to men, or to women in other trachoma endemic countries.

We did not have access to baseline clinical characteristics of operated patients, so reports of improved vision or health post-surgery could not be substantiated by clinical measures. Having these baseline characteristics would also have enabled us to contextualize statements of improved quality of life based on improved clinical pictures.

As part of the study design, we attempted to find and interview women with a variety of ages and clinical presentations; however, we had difficulty locating patients with certain profiles. Specifically, we were able to find only one woman with a post-surgical deformity of the lid margin and only one of the non-operated patients we spoke with was above the age of 40. Interviewing more women with these profiles may have allowed us to determine whether the experiences they described were unique to these specific patients or whether their experiences are more widespread.

We were not able to re-interview participants. Re-interview would have allowed for clarifications on statements made during the initial interview that were not complete or to ask for additional information regarding examples given. Re-interview of patients would have also enabled the study team to ask patients about themes that had emerged in other interviews but not their own and to see if the theme was omitted intentionally or because it was not seen as important by the patient.

Although purpose sampling was used, there may have been some additional bias in participant selection, as certain women had initially thought that the study team was a surgical team. Therefore, women who did not want to be operated may have made themselves absent when the community health workers visited their homes to recruit them into the study. Likewise, some previously operated women may not have presented, thinking that since they had already been operated, the study was not relevant to them.

5.5 Conclusions

In order to eliminate blinding trachoma in Niger by 2015 and worldwide by 2020, the elimination target of one trichiasis case per 1,000 population must be reached. To this end, there has been increased interest in understanding the patient's perspective on trichiasis surgery and reasons why patients fail to present for surgery. Among the women interviewed in this study, the main driver in favor of surgery was the hope of improving health and other indicators of a quality life. In very few cases did patients actually seek out the surgery or pre-plan; rather, they decided to be operated once surgical teams arrived in their villages. Health workers have an enormous influence on these patients, including convincing patients to have the surgery; informing them that their trichiasis is not yet operable; and in giving post-surgical care instructions, indicating a potential to increase patient uptake through better training in pre-surgical patient counseling. Patients reported satisfaction with a wide array of post-surgical outcomes, including major and severe trichiasis.

Many of the most important aspects of living with severe trachoma are social, rather than clinical in nature, and standard burden of disease measures such as DALYs are not currently capturing the "living death" as described by these women. By incorporating trichiasis prior to vision loss or blindness into the current revision of DALYs, a more realistic picture of the burden of disease may be captured, resulting in increased prioritization of elimination efforts at local and global levels.

6.0 Public Health Recommendations

1. This study supports the recalculation of DALYs for trachoma to include an adjustment factor for trachomatous trichiasis itself and not just visual impairment and blindness.
2. Programs should look into how they can reach patients with limited social support and who have been unable to be operated due to the lack of a post-operative caregiver. Programs may consider options such as hospitalizing the women until her sutures are removed to ensure that she is cared for, similar to the model of caring for Guinea worm patients at health centers.
3. Due to the prevalence of post-operative trichiasis and patients' awareness and fear of it, programs should prioritize post-operative follow-up as much as they prioritize the initial surgery. Patients are taking the post-operative advice given seriously but blame themselves for surgical failure and complications, which may prevent them from seeking additional care when needed. Counseling should involve both the patient and caregiver on when bandages and sutures should be removed, appropriate convalescence time, and what to do in case of complications.
4. Messaging around trichiasis surgery should focus on improvement of health and other aspects of quality of life in addition to improving vision. Messaging should be diffused to communities well ahead of the surgical campaign and specifically list time/date/place so that those who want surgery can be present at the time the surgical team arrives. For those not able to attend at the time of the surgical camp, surgeons need to make patients aware of services available at health centers or of forthcoming surgical camps.

5. Health workers and those with trichiasis alike should be made aware that surgical services are available for and should be offered to all patients who want to be operated. Health workers have told women that their trichiasis is not yet ready, possibly allowing their trichiasis to progress and increasing their risk of blindness. Patients need to know that if they desire surgery, they should present and that if they have trichiasis, they are eligible for surgery. The conditions that indicate that surgery is warranted include both the clinical presentation and desire of the patient (International Coalition for Trachoma Control, 2012). In case of patient refusal, programs need to offer alternative strategies for patient care and follow-up, and counsel both the patient and family on the positive and negative aspects of other strategies.
6. Nearly all patients are waiting for surgical campaigns to be operated and either do not know about surgical services available at health centers or do not access these services because of the costs involved. This means that patients may be waiting to be operated while their trichiasis progresses, increasing their risk of blindness. Additional messaging about services offered at health centers should be carried out, and the PNLCC should consider offering free or reduced cost surgery at the clinics during routine care on occasion, perhaps monthly.
7. Trachoma control programs should conduct additional research into the social aspects of the disease, including: a) how stigma affects those with trichiasis and how it influences their ability and desire to seek surgical services; b) how families as a whole and specific family members, especially male members, are affected when a family member has trichiasis; c) perceptions of epilation; d) influences of health workers on patients’ access to and experience with surgery, adherence to postoperative care instructions and follow-

up care; and e) investigating quality of life of a cohort of patients before and after surgery, measuring visual acuity and other clinical aspects of their condition pre- and post-surgery.

References

Amsden, G. W. (2005). Anti-inflammatory effects of macrolides--an underappreciated benefit in the treatment of community-acquired respiratory tract infections and chronic inflammatory pulmonary conditions? *Journal of Antimicrobial Chemotherapy, 55*(1), 10-21. doi: 10.1093/jac/dkh519.

Angel-Urdinola, D., & Woden, Q. (2010). Income generation and intra-household decision making: a gender analysis for Nigeria. J.S. Arbache, A. Kolve, & E. Filipak (Eds.), Gender Disparitites in Africa's Labor Market (381-406). Washington, D.C.: The World Bank.

Bailey, R., Osmond, C., Mabey, D. C.,Whittle, H. C., & Ward, M. E. (1989). Analysis of the household distribution of trachoma in a Gambian village using a Monte Carlo simulation procedure. *International Journal of Epidemiology, 18(4)*, 944-951.

Boubacar, K. (2013a, March). *Etude sur le suivi postoperatoir du trichiasis*, Presentation at the Fourteenth Annual Trachoma Program Review, Atlanta, GA.

Boubacar, K. (2013b, March). *Stratégie CHANCE au Niger*. Presentation at the Fourteenth Annual Trachoma Program Review, Atlanta, GA.

Bowman, R. J., Faal, H., Jatta, B., Myatt, M., Foster, A., Johnson, G. J., & Bailey, R. L. (2002). Longitudinal study of trachomatous trichiasis in The Gambia: barriers to acceptance of surgery. *Investigative Ophthalmology & Visual Sciences, 43(4)*, 936-940.

Bowman, R. J., Soma, O. S., Alexander, N., Milligan, P., Rowley, J., Faal, H., . . . Johnson, G. J. (2000). Should trichiasis surgery be offered in the village? A community randomised trial of village vs. health centre-based surgery. *Tropical Medicine and International Health, 5(8)*, 528-533.

Burton, M. J., Bowman, R. J., Faal, H., Aryee, E. A., Ikumapayi, U. N., Alexander, N. D., . . . Bailey, R. L. (2005). Long term outcome of trichiasis surgery in the Gambia. *British Journal of Ophthalmology, 89(5)*, 575-579. doi: 89/5/575 [pii]10.1136/bjo.2004.055996.

Burton, M. J., Holland, M. J., Faal, N., Aryee, E. A., Alexander, N. D., Bah, M., . . . Bailey, R. L. (2003). Which members of a community need antibiotics to control trachoma? Conjunctival Chlamydia trachomatis infection load in Gambian villages. *Investigative Ophthalmology & Visual Sciences*, 44(10), 4215-4222.

Burton, M. J., & Mabey, D. C. (2009). The global burden of trachoma: a review. *PLoS Neglected Tropical Diseases, 3(10)*, e460. doi: 10.1371/journal.pntd.0000460.

Burton, M. J., Rajak, S. N., Ramadhani, A., Weiss, H. A., Habtamu, E., Abera, B., . . . Bailey, R. L. (2012). Post-operative recurrent trachomatous trichiasis is associated with increased conjunctival expression of S100A7 (psoriasin). *PLoS Negl Trop Dis, 6*(12), e1985. doi: 10.1371/journal.pntd.0001985

Carr, A. J., Higginson, I. J., & Robinson, P. G. (Eds.). (2003). *Quality of Life*. London: BMJ Books.

CIA. (2013). Niger. *CIA World Factbook*. Retrieved April 13, 2013, 2013, from https://www.cia.gov/library/publications/the-world-factbook/geos/ng.html.

Congdon, N., West, S., Vitale, S., Katala, S., & Mmbaga, B. B. O. (1993). Exposure to children and risk of active trachoma in Tanzanian women. *American Journal of Epidemiology, 137(3),* 366-372.

Courtright, P., Chirambo, M., Lewallen, S., Chana, H., & Kanjaloti, S. (2000). *Collaboration with African Traditional Healers for the Prevention of Blindness*. Singapore: World Scientific Publishing Co. Pte. Ltd.

Courtright, P., & West, S. K. (2004). Contribution of sex-linked biology and gender roles to disparities with trachoma. *Emerging Infectious Diseases, 10(11),* 2012-2016. doi: 10.3201/eid1011.040353.

Cromwell, E. A., Courtright, P., King, J. D., Rotondo, L. A., Ngondi, J., & Emerson, P. M. (2009). The excess burden of trachomatous trichiasis in women: a systematic review and meta-analysis. *Transactions of the Royal Society of Tropical Medicine and Hygiene, 103(10),* 985-992. doi: 10.1016/j.trstmh.2009.03.012.

Dhaliwal, U., Nagpal, G., & Bhatia, M. S. (2006). Health-related quality of life in patients with trachomatous trichiasis or entropion. *Ophthalmic Epidemiology, 13(1),* 59-66. doi: 10.1080/09286580500473803.

Duflo, E. (2012). Women empowerment and economic development. *Journal of Economic Literature*, *50(4),* 1051-1079.

Emerson, P. M., Bailey, R. L., Walraven, G. E., & Lindsay, S. W. (2001). Human and other faeces as breeding media of the trachoma vector *Musca sorbens*. *Medical and Veterinary Entomology, 15(3),* 314-320.

Emerson, P. M., Frost, L., Bailey, R., & Mabey, D. (2006). I*mplementing the SAFE strategy for trachoma control: a toolbox of interventions for promoting facial cleanliness and environmental improvement*. Atlanta: The Carter Center.

Emerson, P. M., Lindsay, S. W., Alexander, N., Bah, M., Dibba, S. M., Faal, H. B., . . . Bailey, R. L. (2004). Role of flies and provision of latrines in trachoma control: cluster-randomised controlled trial. *Lancet, 363(9415),* 1093-1098. doi: 10.1016/s0140-6736(04)15891-1.

EuroQol Group. (2009). EQ-5D. Rotterdam: EuroQol Group.

Frick, K. D., Hanson, C. L., & Jacobson, G. A. (2003). Global burden of trachoma and economics of the disease. *American Journal of Tropical Medicine and Hygiene, 69(5 Suppl),* 1-10.

Frick, K. D., Melia, B. M., Buhrmann, R. R., & West, S. K. (2001). Trichiasis and disability in a trachoma-endemic area of Tanzania. *Archives of Ophthalmology, 119(12),* 1839-1844.

Hotez, P. J., & Kamath, A. (2009). Neglected Tropical Diseases in Sub-Saharan Africa: Review of Their Prevalence, Distribution, and Disease Burden. *PLoS Neglected Tropical Diseases, 3*(8), e412. doi: 10.1371/journal.pntd.0000412.

International Coalition for Trachoma Control. (2011). *The End is INSight*. Decatur: International Coalition for Trachoma Control.

International Coalition for Trachoma Control. (2012). Global Scientific Meeting on Trachomatous Trichiasis. Decatur: International Coalition for Trachoma Control.

IQOLA Project. (1990). SF-36. Retrieved March 3, 2012 from http://www.iqola.org/.

Johnson, G. J., Minassian, D. C., Weale, R. A., & West, S. K. (Eds.). (2012). *The Epidemiology of Eye Disease* (3rd ed.). London: Imperial College Press.

Khandekar, R., Mohammed, A. J., & Courtright, P. (2001). Recurrence of trichiasis: a long-term follow-up study in the Sultanate of Oman. *Ophthalmic Epidemiology, 8(2-3),* 155-161.

Leplège, A., Schémann, J. F., Diakité, B., Touré, O., Ecosse, E., Jaffre, Y., & Dumestre, G. (2006). A new condition specific quality of life measure for the blind and the partially sighted in Sub-Saharan Africa, the IOTAQOL: Methodological aspects of the development procedure. *Quality of Life Research, 15(8),* 1373-1382. doi: 10.1007/s11136-006-0023-y.

Litt, E., Baker, M. C., & Molyneux, D. (2012). Neglected tropical diseases and mental health: a perspective on comorbidity. *Trends in Parasitology, 28(5),* 195-201. doi: 10.1016/j.pt.2012.03.001.

Mahande, M., Tharaney, M., Kirumbi, E., Ngirawamungu, E., Geneau, R., Tapert, L., & Courtright, P. (2007). Uptake of trichiasis surgical services in Tanzania through two village-based approaches. *British Journal of Ophthalmology, 91(2),* 139-142. doi: 10.1136/bjo.2006.103374.

Malik, K. (2013). *Human Development Report 2013* (pp. 2013). New York: UNDP.

Margraf, J., Meyer, A. H., & Lavallee, K. L. (2013). Well-being from the knife? Psychological effects of aesthetic surgery. *Clinical Psychological Science, 1(2).* doi: 10.1177/2167702612471660.

Mauss, M. (1925). *Essai sur le don, forme archaïque de l'échange*. Paris: Felix Alcan.

Ministère de la Santé Publique. (2006). Plan d'action national de lutte intégrée contre les maladies tropicales negligees au Niger, 2007 - 2010. Niamey: Ministère de la Sante Publique.

Moen, P., Dempster-McClain, E., & Williams, R., Jr. (1989). Social integration and longevity: an event history analysis of women's roles and resilience. *American Sociological Review, 54(4)*, 635-647.

Murray, C. J., & Acharya, A. K. (1997). Understanding DALYs (disability-adjusted life years). *Journal for Health Economics, 16*(6), 703-730.

Murray, C. J., Vos, T., Lozano, R., Naghavi, M., Flaxman, A. D., Michaud, C., . . . Memish, Z. A. (2012). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: A systematic analysis for the Global Burden of Disease Study 2010. *Lancet, 380(9859)*, 2197-2223. doi: 10.1016/s0140-6736(12)61689-4.

Ngondi, J., Matthews, F., Reacher, M., Onsarigo, A., Matende, I., Baba, S., . . . Emerson, P. (2007). Prevalence of risk factors and severity of active trachoma in southern Sudan: An ordinal analysis. *American Journal of Tropical Medicine and Hygiene, 77(1)*, 126-132.

Nijkamp, M. D., Nuijts, R. M. M. A., van den Borne, B., Webers, C. A. B., van der Horst, F., & Hendrikse, F. (2000). Determinants of patient satisfaction after cataract surgery in 3 settings. *Journal of Cataract & Refractive Surgery, 26(9)*: 1379-1388.

Oliva, M. S., Muñoz, B., Lynch, M., Mkocha, H., & West, S. K. (1997). Evaluation of barriers to surgical compliance in the treatment of trichiasis. *International Ophthalmology, 21(4),* 235-241.

Ono, K., Hiratsuka, Y., & Murakami, A. (2010). Global inequality in eye health: country-level analysis from the Global Burden of Disease Study. *American Journal of Public Health, 100*(9), 1784-1788. doi: 10.2105/ajph.2009.187930.

Palmer, S.L., Dickman, L.M., Toubali, E., Mosher, A.W., Cromwell, E.A., Zerihun, M., . . . Burton, M.J. (2012). Understanding trichiasis from the perspective of the patient: an assessment of previously operated and never operated patients to improve the quality and efficiency of surgical services in Ethiopia, Niger, and Mali. Unpublished manuscript.

Pascolini, D., Mariotti, S. P., Pokharel, G. P., Pararajasegaram, R., Etya'ale, D., Negrel, A. D., & Resnikoff, S. (2004). 2002 global update of available data on visual impairment: A compilation of population-based prevalence studies. *Ophthalmic Epidemiology, 11(2),* 67-115.

Patterson, A. E. (2012). *Net values: meaning, motivation and measurement in the distribution, use and monitoring of bed nets for malaria control in Ségou, Mali.* (Unpubished doctoral dissertation). Emory University, Atlanta, GA.

Pruss, A., Kay, D., Fewtrell, L., & Bartram, J. (2002). Estimating the burden of disease from water, sanitation, and hygiene at a global level. *Environmental Health Perspectives, 110(5),* 537-542.

Rabiu, M. M., & Abiose, A. (2001). Magnitude of trachoma and barriers to uptake of lid surgery in a rural community of northern Nigeria. *Ophthalmic Epidemiology, 8(2-3),* 181-190.

Rajak, S. N., Collin, J. R., & Burton, M. J. (2012). Trachomatous trichiasis and its management in endemic countries. *Surv Ophthalmol, 57(2),* 105-135. doi: 10.1016/j.survophthal.2011.08.002.

Rajak, S. N., Habtamu, E., Weiss, H. A., Bedri, A., Gebre, T., Bailey, R. L., . . . Burton, M. J. (2011a). The clinical phenotype of trachomatous trichiasis in Ethiopia: not all trichiasis is due to entropion. *Investigative Ophthalmology & Visual Sciences, 52(11),* 7974-7980. doi: 10.1167/iovs.11-7880.

Rajak, S. N., Habtamu, E., Weiss, H. A., Bedri, A., Zerihun, M., Gebre, T., . . . Burton, M. J. (2012). Why do people not attend for treatment for trachomatous trichiasis in Ethiopia? A study of barriers to surgery. *PLoS Neglected Tropical Diseases, 6(8),* e1766. doi: 10.1371/journal.pntd.0001766.

Rajak, S. N., Habtamu, E., Weiss, H. A., Kello, A. B., Gebre, T., Genet, A., . . . Burton, M. J. (2011b). Surgery versus epilation for the treatment of minor trichiasis in Ethiopia: a randomised controlled noninferiority trial. *PLoS Medicine, 8(12)*, e1001136. doi: 10.1371/journal.pmed.1001136.

Reacher, M., A., F., & Huber, J. (1998). *Trichiasis surgery for trachoma: The bilamellar tarsal rotation procedure*. Geneva: World Health Organization.

Schémann, J. F., Leplège, A., Keita, T., & Resnikoff, S. (2002). From visual function deficiency to handicap: Measuring visual handicap in Mali. *Ophthalmic Epidemiology, 9(2),* 133-148.

Seeman, T. E. (1996). Social ties and health: the benefits of social integration. *Annals of Epidemiology, 6(5),* 442-451.

Solomon, A. W., Holland, M. J., Burton, M. J., West, S. K., Alexander, N. D. E., Aguirre, A., . . . Mabey, D. C. W. (2003). Strategies for control of trachoma: observational study with quantitative PCR. *Lancet, 362,* 198-204.

Tarlov, A. R., Ware, J. E., Jr., Greenfield, S., Nelson, E. C., Perrin, E., & Zubkoff, M. (1989). The Medical Outcomes Study: An application of methods for monitoring the results of medical care. *JAMA, 262(7)*, 925-930.

Taylor, H. R., West, S. K., Mmbaga, B. B., Katala, S. J., Turner, V., Lynch, M., . . . Rapoza, P. A. (1989). Hygiene factors and increased risk of trachoma in central Tanzania. *Archives of Ophthalmology, 107*(12), 1821-1825.

The Carter Center. (2009). *Women and trachoma: achieving gender equity in the implementation of SAFE*. Atlanta: The Carter Center.

The Carter Center (2010). Unpublished raw data.

Thylefors, B., Dawson, C. R., Jones, B. R., West, S. K., & Taylor, H. R. (1987). A simple system for the assessment of trachoma and its complications. *Bulletin of the World Health Organization, 65*(4), 477-483.

UNICEF (2006). *The state of the world's children 2007*. New York: UNICEF.

van Dijk, K., Lewallen, S., Chirambo, M., Gardiner, J., Hoar, B., Lindley, J., . . . Courtright, P. (1999). Creation and testing of a practical visual function assessment for use in Africa: correlation with visual acuity, contrast sensitivity, and near vision in Malawian adults. *British Journal of Ophthalmology, 83*(7), 792-795.

West, E. S., Mkocha, H., Munoz, B., Mabey, D., Foster, A., Bailey, R., & West, S. K. (2005). Risk factors for postsurgical trichiasis recurrence in a trachoma-endemic area. *Investigative Ophthalmology & Visual Sciences, 46(2)*, 447-453. doi: 10.1167/iovs.04-0600.

West, S., Lynch, M., Munoz, B., Katala, S., Tobin, S., & Mmbaga, B. B. (1994). Predicting surgical compliance in a cohort of women with trichiasis. *International Ophthalmology, 18*(2), 105-109.

West, S., Nguyen, M. P., Mkocha, H., Holdsworth, G., Ngirwamungu, E., Kilima, P., & Munoz, B. (2004). Gender equity and trichiasis surgery in the Vietnam and Tanzania national trachoma control programmes. *British Journal of Ophthalmology, 88(11)*, 1368-1371. doi: 10.1136/bjo.2004.041657.

West, S. K. (2011). Trichiasis recurrence—Why the surgery part of trachoma control is still uncontrolled. *US Ophthalmic Review, 4(1)*, 77-79.

West, S. K., Bedri, A., Ton, T. K. T., West, E. S., & Mariotti, S. P. (2005). *Final Assessment of Trichiasis Surgeons.* Geneva: World Health Organization.

West, S. K., West, E. S., Alemayehu, W., Melese, M., Munoz, B., Imeru, A., . . . Quinn, T. (2006). Single-dose azithromycin prevents trichiasis recurrence following surgery:

randomized trial in Ethiopia. *Archives of Ophthalmology, 124(3),* 309-314. doi: 10.1001/archopht.124.3.309.

Wolfson, E. M., Fedwa, L., & Young, S. A. (1997). *Trachoma: a women's health issue.* New York: Global Alliance for Women's Health.

Wolle, M. A., Cassard, S. D., Gower, E. W., Munoz, B. E., Wang, J., Alemayehu, W., & West, S. K. (2011). Impact of Trichiasis surgery on physical functioning in Ethiopian patients: STAR trial. *American Journal of Ophthalmology, 151(5),* 850-857. doi: 10.1016/j.ajo.2010.10.039.

World Health Organization. (1997). WHOQOL: Measuring quality of Life. Geneva: World Health Organization.

World Health Organization (2004). WHOQOL-BREF. Geneva: World Health Organization.

World Heath Organization (2012). Global Alliance for the Elimination of Blinding Trachoma by 2020. *Weekly Epidemiological Record, 87(17),* 161-168.

Wright, H. R., Turner, A., & Taylor, H. R. (2007). Trachoma and poverty: Unnecessary blindness further disadvantages the poorest people in the poorest countries. *Clinical and Experimental Optometry, 90(6),* 422-428. doi: 10.1111/j.1444-0938.2007.00218.x.

Appendix I
Screening Form For Trichiasis Patients (Operated and Unoperated)
English Translation

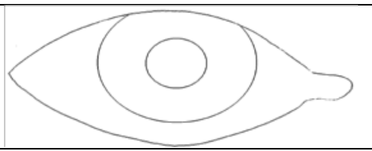
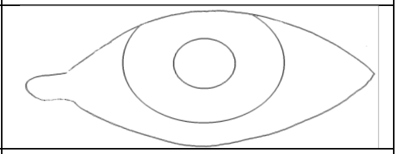
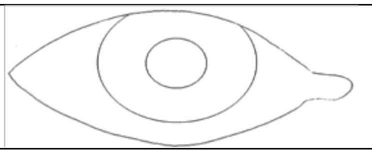
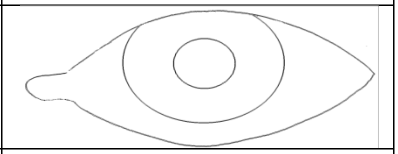
Consent

Consent for clinical examination? **0=no** **1=yes**	
Consent for interview? **0=no** **1=yes**	

Demographic Information

First name	
Last (father's) name	
Village of residence (last 6 months)	
District	
Region	
Age (years)	
Date/place of most recent surgery (if operated)	
Number of times operated	

Clinical examination

Question	Right Eye	Left Eye
Eye was operated? 0=no 1=yes		
Severity of Trichiasis 0=none (0 lashes or evidence of epilation) 1=mild (1-4 lashes) 2=major (5-10 lashes) 3=severe (>10 lashes)		
Where do the lashes touch the eye? 1=center of cornea 2=non-central part of cornea 3=lateral global/no cornea 4=do not touch globe		
Draw the eyelashes that touch the globe.		
Eye currently epilated? 0=no 1=yes		
Presence of corneal opacity? 0=no 1=yes		
Draw location of the corneal opacity.		
If operated, evidence of post-operative trichiasis? 0=no 1=yes		
If operated, evidence of lid contour defect ? 0=no 1=yes		
If so, please describe.		

Presence of other ocular morbidity? 0=no 1=yes		
If so, please describe.		

Appendix II
Screening Form For Friend of Trichiasis Patient
English Translation

Consent

Consent for interview? **0=no** **1=yes**	

Demographic

First name	
Last (father's) name	
Village of residence (last 6 months)	
District	
Region	
Age (years)	
Relationship to trichiasis case/patient	
Years known trichiasis case/patient	

Appendix III
Screening Form For Head of Household for Focus Group Discussions
English Translation

Consent

Consent for focus group? **0=no** **1=yes**	

Demographic

First name	
Last (father's) name	
Village of residence (last 6 months)	
District	
Region	
Age (years)	
Relationship to trichiasis case/patient	
Years known trichiasis case/patient	

Knowledge of Trichiasis/Trichiasis Surgery

Are you aware of a disease of condition in which eye lashes touch the eye? Yes_____ No_____

Do you know anyone with that disease/condition? Yes_____ No_____ If so, whom?

What happens if someone has trichiasis?

What can be done if someone has trichiasis?

(If participant responds "surgery" or "operate" then ask the next question)
Where can someone go for surgery if they have trichiasis?

Appendix IV
Thematic Interview Guide: Operated Trichiasis Patients
English Translation

Opening Question

What does it mean to have a good life?

Theme 1: Development of trichiasis/experience with trichiasis

1. Tell me about when you first noticed your eye problem.

Follow-up Questions:

a. Describe how your eyes felt.
b. How would you describe the appearance of your eyes at that time?

2. What happened to your eyes over time?

Follow-up Questions:

a. How did the way your eyes feel change from when you first noticed the problem?
b. How did the way your eyes look change from when you first noticed the problem?
c. How did your eye problem affect your life before surgery?
d. How does it affect it now?

Theme 2: Perceptions about Trichiasis/Trichiasis Surgery

1. What do you know about trichiasis?

2. What have been the positive things you have experienced from your surgery?

3. What have been the negative things you have experienced from your surgery?

Follow-up Questions:

a. When should someone with trichiasis be operated?
b. When should they not be operated?

Theme 3: Perceptions about Physical Health/Activities of Daily Living

1. What activities/tasks/chores do you and other women in your community do daily?

2. How well were you able to do these activities after your eye problems began but before you had surgery?

Follow-up Questions:

If the person experienced difficulties:

a. What tasks did you have difficulty with?
b. Describe the difficulty you had with these tasks.

3. How well are you currently able to do these activities?

Follow-up Questions:

If the person is still experiencing difficulty:
a. What tasks do you still have difficulty with?

4. Describe your ability to get around to perform your daily activities before the surgery.

Follow-up Questions:
a. How well were you able to get around your compound?
b. How well were you able to get around your village?
c. How well were you able to travel to neighboring villages?

5. Describe your current ability to get around to perform your daily activities.

Follow-up Questions:
d. How well are you able to get around your compound?
e. How well are you able to get around your village?
f. How well are you able to travel to neighboring villages?

Theme 3: Perceptions about Family/Community Support or Assistance

1. Tell me about the last time that you needed assistance with (task(s) mentioned above).

Follow-up Questions:
a. How do you let others know when you need assistance?
b. How does it make you feel when you need assistance?

2. How did family members treat you when you developed this eye problem?

   Follow-up Question
   a. How did other community members treat you?
   b. How did this make you feel?

3. How have family members treated you since you had surgery for your trichiasis?

   Follow-up Question
   a. How have other community members treated you?

4. How did trichiasis affect your relationship with (husband, children, friends, etc.)?

5. How has the surgery changed this?

Theme 4: Perceptions of general health status

1. How would you describe your overall health before surgery?

2. How has your health changed since you had trichiasis surgery?

Follow-up Questions:

a. In the last week, how often has your health kept you from doing your normal activities? *(If the patient responds, "never," then ask: "and in the last month?")*

Theme 5: Decision-making

1. Tell me about the last time someone in your family needed to go to a health center (CSI, health post, hospital) for care.

Follow-up Questions:

a. How did the family members know that the person needed care from the health center?
b. Which family members helped to make the decision?
c. What factors did the family consider in making the decision?

2. Tell me about the role women have in making decisions.

3. For what types of activities or things do you need permission from someone else?

4. If you want permission to do something, what do you do?

Follow-up Questions

a. What do you do to persuade (those persons mentioned above)?
b. When do you approach (these persons)?
c. How do other household members help you to convince (those persons)?

Closing Questions

1. Thinking back to what you said about what a good life is and what you've told me today about living with trichiasis, how did trichiasis affect your ability to live "a good life"?
2. How has surgery affected it?

Appendix V
Thematic Interview Guide: Unoperated Trichiasis Cases
English Translation

Opening Question

What does it mean to have a good life?

Theme 1: Development of trichiasis/experience with trichiasis

2. Tell me about when you first noticed your trichiasis.

Follow-up Questions:

c. Describe how your eyes felt at that time.
d. How would you describe the appearance of your eyes at that time?

3. What, if anything, has happened to your eyes since you first noticed the problem?

Follow-up Questions:

e. Describe how your eyes feel now.
f. Describe the appearance of your eyes now.
g. In what ways, if any, has trichiasis affected your life?

Theme 2: Perceptions about Physical Health/Activities of Daily Living

6. What activities/tasks/chores do you and other women in your community do daily?

7. How well are you able to do these activities?

Follow-up Questions:

If the person is experiencing difficulties:

c. What tasks do you have difficulty with?
d. Describe the difficulty you have with these tasks.
e. Describe the difficulty you have with these tasks now versus when you first noticed your eye condition.

8. Describe your ability to get around to perform your daily activities.

Follow-up Questions:

g. How well are you able to get around your compound?
h. How well are you able to get around your village?
i. How well are you able to travel to neighboring villages?

Theme 3: Perceptions about Family/Community Support or Assistance

6. Tell me about the last time that you needed assistance with the task(s) mentioned above *(list tasks one by one and wait for responses)*.

Follow-up Questions:
c. How do you let others know when you need assistance?
d. How does it make you feel when you need assistance?

7. How have family members treated you since you developed this condition?

   Follow-up Question
   c. How do other community members treat you?

8. How has trichiasis affected your relationship with (husband, children, friends, etc.)?

Theme 4: Perceptions about Trichiasis/Trichiasis Surgery

4. What do you know about trichiasis?

5. If you have ever sought any type of treatment for trichiasis, tell me about the last time.

If the patient does not mention surgery, ask: what have you heard about surgery available for trichiasis?

Follow-up Questions:
a. Tell me about the benefits and disadvantages of the surgery.
b. When should someone with trichiasis be operated?
c. When should they not be operated?
d. What considerations should be thought about before someone is operated for trichiasis?

Theme 5: Decision-making

5. Tell me about the last time someone in your family needed to go to a health center (CSI, health post, hospital) for care.

Follow-up Questions:
d. How did the family members know that the person needed care at the health center?
e. Which family members helped to make the decision?
f. What factors did the family consider in making the decision?

6. Tell me about the role women in the household have in making decisions.

7. If you want permission to do something, what do you do?

Follow-up Questions

d. What do you do to persuade (those persons mentioned above)?
e. How do you approach (these persons)?
f. How do other household members help you to convince (those persons)?

Closing Question

Thinking back to what you said about what a good life is and what you’ve told me today about living with trichiasis, how has trichiasis affected your ability to live “a good life”?

Appendix VI
Thematic Interview Guide: Heads of Households
English Translation

Theme 1: Perceptions of Trichiasis

6. What do you know about trichiasis?

7. Tell me about your family member's experience with trichiasis.

   Follow-up Question
   a. How did trichiasis affect their day to day activities?
   b. How was your family member treated?
   c. How has this family member's trichiasis impacted you personally?

Theme 2: Decision-making

8. Tell me about the last time someone in your family needed to go to a health center (CSI, health post, hospital) for care.

Follow-up Questions:
g. How did you know that the person needed care from the health center?
h. Which family members helped to make the decision?
i. What factors were considered when making the decision?

9. What have you heard about trichiasis surgery?

   Follow-up Question
   a. Tell me about the benefits and disadvantages of the surgery.
   b. When should someone with trichiasis be operated?
   c. When should they not be operated?

10. Tell me about the role women have in making decisions.

    Follow-up Question
    a. What role do women have in making decisions for their health?
    b. How would a female member of your household let you know if she needed care?