2014

Glaucoma Care in Low-Resource Environments

Natalya Surmachevska
Lehigh University

GLAUCOMA CARE IN LOW-RESOURCE ENVIRONMENTS

by

Natalya Surmachevska

A Thesis

Presented to the Graduate and Research Committee

of Lehigh University

in Candidacy for the Degree of

Master of Arts

in

Sociology

Lehigh University

April 25th, 2014

Thesis is accepted and approved in partial fulfillment of the requirements for the Master of Arts in Sociology.

Glaucoma Care in Low-Resource Environments
Natalya Surmachevska

_____

Date Approved

_____

Dr. Judith N. Lasker, Ph.D.
Thesis Advisor

_____

Dr. Kelly F. Austin, Ph.D.
Committee Member

_____

Mark Orrs, M.Phil.
Committee Member

_____

Dr. Nicola Tannenbaum, Ph.D.
Department Chair

I would like to thank Dr. Judith N. Lasker, my thesis advisor, who worked with me for over a year on this research and read the thesis at each stage of each draft, contributing helpful suggestions and insight from her many years of work in medical sociology. I would also like to thank Dr. Kelly Austin and Prof. Mark Orrs, my two other committee members, who read and commented on the proposal and thesis prior to its submission. I would like to thank Dr. Paul Jorizzo, MD for looking over the clinical aspects of the thesis. I would like to thank Troy Boni from the Lehigh Office of Research and Sponsored Programs for being a key resource throughout the IRB-approval process. Lastly, I would like to thank Lehigh University's Social Science Research Center, Office of the Vice President and Associate Provost for Research and Graduate Studies, and the Department of Sociology & Anthropology for providing funds that allowed me to carry out this research.

Table of Contents

List of Tables ..... **vii**

List of Figures ..... **vii**

Abstract **1**

Introduction **2**
Glaucoma 3
Prevalence 3
Types of glaucoma 5
Diagnosis 7
Treatment 7
Unite For Sight and Partner Clinics 9

Theoretical Insight **12**
Health Belief Model 12
Socio-Ecological Model 14

Barriers to Glaucoma Care **15**
Structural Barriers 17
Structural Barriers in Ghana and India 20
Economic Barriers 22
Economic Barriers in Ghana and India 25
Psychological Barriers 28
Psychological Barriers in Ghana and India 30
Socio-Cultural Barriers 33
Socio-Cultural Barriers in Ghana and India 34
Note about Barriers 36

Methods **37**
Quantitative Methodology 37
Qualitative Methodology 38

Results **41**
Quantitative Data Analysis 41
Description of the Data 41
Demographics of the Patient Population 42
Measuring Visual Acuity 43
Visual Acuity of the Patient Population 44
Prevalence of Glaucoma 44
Glaucoma and Other Diagnoses 44
Demographics of Glaucoma 45
Quantitative Discussion 48
Limitations 50
Qualitative Data Analysis 51
Barriers to Understanding Prevalence 51
Understanding Prevalence: Program-Side Barriers in Ghana and India 52

Understanding Prevalence: Patient-Side Barriers in Ghana and India 55
Barriers to Diagnosis 55
Diagnosis: Program-Side Barriers in Ghana and India 57
Diagnosis: Patient-Side Barriers in Ghana and India 63
Barriers to Treatment 66
Treatment: Program-Side Barriers in Ghana and India 67
Treatment: Patient-Side Barriers in Ghana and India 73
Qualitative Discussion 78
Limitations 80

Conclusion 82

References 84

Appendix 89

Vita 98

List of Tables

Table 1	Age Distribution of Patient Population, 3 Categ.	Appendix, Page 89
Table 2	Age Distribution of Patient Population, 8 Categ.	Appendix, Page 89
Table 3	Age & Sex Distribution of Patient Population	Appendix, Page 90
Table 4	Visual Acuity of the Patient Population	Appendix, Page 91
Table 5	Prevalence of Diagnoses	Appendix, Page 91
Table 6	Glaucoma & Age Distribution	Appendix, Page 92
Table 7	Glaucoma by Village/Outreach Location	Appendix, Page 93
Table 8	Age Distribution by Village/Outreach	Appendix, Page 93
Table 9	Glaucoma Prevalence at Different Acuity Levels	Appendix, Page 94

List of Figures

Figure 1	Approximation of Vision with Different Acuities	Appendix, Page 95
Figure 2	Progression of Glaucoma	Appendix, Page 96
Figure 3	Qualitative Framework	Appendix, Page 96
Figure 4	Qualitative Results Summary	Appendix, Page 97

Abstract

This thesis explores the barriers to glaucoma care in low-resource environments within the context of a non-profit organization (Unite For Sight) and partner clinics working in two countries – Ghana and India. The Health Belief and Socio-Ecological Models form the theoretical background of glaucoma care delivery. A literature review looks at barriers to glaucoma care for programs and patients from structural, economic, psychological, and socio-cultural perspectives. Following the literature review, the quantitative and qualitative methods are explained – a de-identified patient dataset to evaluate glaucoma prevalence at outreaches in Ghana, and field work observations from Ghana and India (in the form of blog entries) that elucidate the barriers to glaucoma care.

Prevalence of glaucoma is found to be very high at Unite For Sight partner clinic outreaches near Kumasi, Ghana in July 2013 – 28.17% of patients got the diagnosis. The analysis shows glaucoma has an early onset in Ghanaian clinic patients, is asymptomatic (23.60% of patients with normal vision have glaucoma), increases nonlinearly with age, has no relationship to sex, and differs significantly by outreach location, perhaps due to the age distributions at outreaches. The limitations of the data are explored.

The qualitative data shows that barriers to glaucoma care occur at three levels – barriers to understanding prevalence, barriers to diagnosis, and barriers to treatment. Each of these occurs via either a structural/economic or psychological/socio-cultural mechanism, for both the program and the patient. Barriers include lack of research on glaucoma, program structure that does not fully address glaucoma, and complex patient barriers to successful glaucoma care.

Introduction

Approximately 60.5 million people worldwide have glaucoma, and 8.4 million are blind from the disease (Ravi 2012). 75% of glaucoma occurs in the developing world (Schwab 2007:99). These statistics alone suggests the importance of addressing glaucoma prevalence, diagnosis, and treatment in low-resource environments. Furthermore, the typically asymptomatic nature of the disease until the late stages, the inability to prevent it from occurring, and the irreversibility of vision loss (as opposed to cataract) makes it a particularly sinister and therefore crucial disease to address if attempting to reduce the prevalence of blindness worldwide. Unfortunately, 50-90% of true glaucoma patients remain undiagnosed, and this figure is closer to 90% in low-resource environments (Nayak et al 2011). The lack of glaucoma care is partly based on poor understanding of glaucoma prevalence and is accompanied by lack of access to diagnosis and treatment.

These three levels of care (prevalence, diagnosis, and treatment) are influenced by four barriers to care: structural, economic, psychological, and socio-cultural. The following thesis includes a literature review of these barriers, from a general as well as a resource-limited context, particularly Ghanaian and Indian. The goal of this research is to further elucidate these barriers, which were observed at Unite For Sight partner clinic outreaches in Ghana as well as in Chennai, India. A mixed methods approach is used to accomplish this goal. A de-identified (name-free and birthdate-free) patient dataset illustrates the geographic distribution of glaucoma at Unite For Sight outreaches in Ghana, to document overall prevalence in the Ghanaian clinic patients (but not of Ghana in general, because the sample is not random). A month-long series of my blog entries –

the mechanism for recording field notes – was analyzed thematically for specific structural, economic, psychological, and socio-cultural barriers to care seen in Ghana; a 10-day series of my blog entries from Chennai, India was used to compare the barriers in Ghana to the ones in Chennai, India. Ultimately, the research can be used by Unite For Sight to improve their work on glaucoma in both countries and can also be used by other organizations and individuals working on glaucoma care in low-resource environments.

Work to improve glaucoma diagnosis and treatment is crucial for patients with the condition, as maintaining their vision health allows them to live active and productive lives, contributing to the growth of their communities. An ignorance of the barriers to glaucoma care will continue to reinforce the vast disparities in access to glaucoma diagnosis and treatment around the world (Nayak et al 2011). Such disparities must be addressed if we are interested in diagnosing and treating patients with glaucoma in an equitable way, regardless of their socioeconomic position and material conditions.

Glaucoma

Glaucoma is a chronic progressive disease of the optic nerve associated with increased intraocular pressure that causes progressive vision loss. Glaucoma is not preventable, although some risk factors predispose an individual to glaucoma. It is manageable with a variety of medical and surgical techniques (Schwab 2007).

Prevalence

Glaucoma is the second leading cause of blindness in the world after cataracts. It accounts for 12% of the world's blindness (WHO 2013). As previously mentioned, 75% of glaucoma occurs in the developing world (Schwab 2007:99). In Ghana, glaucoma is

"the most common cause of irreversible blindness" (Ntim-Amponsah et al 2004b). Prevalence increases slightly with age in Ghanaian communities – 7.7% for people 30 years old and under, increasing to 8.5% for people 40 years and older – but is considered predominantly a disease of the elderly in most (Western) literature. According to some studies in Ghana, prevalence does not seem to differ significantly by gender nor by ethnic group in diverse metropolitan areas (Ntim-Amponsah et al 2004b). However, Ntim-Amponsah (2004b) looked only at locations with ethnically diverse populations (attempting to study prevalence by ethnic group), perhaps missing locations that are ethnically homogeneous which may have different (or higher) glaucoma prevalence due to the heritability of glaucoma. Additionally, there is a rural versus urban distinction in the severity of visual field loss due to glaucoma, in that rural patients tend to have more severe visual field loss due to lack of access to diagnosis and treatment (Ntim-Amponsah 2002).

However, it is important not to extrapolate the prevalence in Ghana to that of prevalence in all of Africa or to all "blacks", as prevalence in parts of rural Northern Nigeria, for example, has been reported as low as 1.02% of the population (Murdoch et al 2001). Prevalence of glaucoma in Africans and people of African descent varies significantly – from 8% in a study in Ghana, to 9.6% in a study of a population in St. Lucia, to 3.5% in urban South Africa (Budenz et al 2013:655). Comprehensive Ghana-specific regional studies that look at the factor of age, heritage, socioeconomic class, and rural/urban distinction are not present in the literature, suggesting a space for new research.

In India, the prevalence is somewhat lower compared to Ghana. India is made up of various ethnic groups and thus prevalence likewise varies by region. Population-based surveys have found the prevalence to be 6.1% in Hyderabad, Andhra Pradesh, 3.2% in Madurai, Tamil Nadu, and 3.4% in Calcutta, West Bengal; in Dhaka, Bangladesh, the prevalence is 2.4% (Raychaudhuri et al 2005). Thus, prevalence varies from region to region in India, and certainly between countries on the Indian Subcontinent/Southeast Asia. Rural populations in south India (where Chennai is located) have a prevalence of around 1.62%, with 98.5% of the population not being aware of the disease (Vijaya et al 2005). Urban studies in south India show slightly higher prevalence of 4.32%, perhaps explained by the more advanced techniques available in urban areas that more accurately diagnose glaucoma (Jacob et al 1998). A population-based study in Chennai found higher rates of glaucoma in patients who have undergone cataract surgery, as glaucoma is a potential complication following eye surgery (George et al 2010). Thus, the somewhat lower prevalence in India is not to suggest that glaucoma is less important to address in this environment, especially as aging populations have access to cataract surgeries from which glaucoma can develop.

Types of glaucoma

The optic nerve is the part of the eye that becomes damaged in glaucoma, leading to glaucomatous loss of vision. The main mechanism for glaucoma is obstruction of the trabecular meshwork, where intraocular fluid leaves the anterior (front) chamber of the eye, causing increased intraocular pressure (Schwab 2007:99).

There are several types of glaucoma. First, glaucoma can be categorized into primary and secondary – occurring on its own or precipitated by another eye condition (such as trauma to the eye, diabetes, or eye infection) or by eye surgery (such as cataract removal). Primary glaucoma can be further subdivided into primary open-angle and primary angle closure glaucoma. Open-angle glaucoma is a disease in which materials in the eye such as proteins or pigment deposit in the trabecular meshwork. Angle closure glaucoma occurs in smaller, farsighted eyes where the meshwork is obstructed by the iris. Open-angle glaucoma tends to be chronic and is "more prevalent and more severe in patients of African origin or descent"; angle-closure glaucoma can be both acute and chronic and is described by general textbook sources and academic literature as "most common in Asian populations, particularly in India and China" (Schwab 2007:101).

The quantitative aspect of this research will address chronic primary glaucoma (as the data distinguishes between chronic versus traumatic/acute), without distinction of whether it is open or closed-angle. This is because data available for this research does not specify whether a patient's glaucoma diagnosis is of closed versus open angle, although open-angle is presumably the most prevalent type among patients at Unite For Sight outreaches in Ghana, given that only about 6.6% of Ghanaian glaucoma patients have angle-closure glaucoma (Herndon et al 2002). Similarly, the qualitative aspect of this research speaks about glaucoma generally, not specifying closed or open-angle. Regardless of whether the glaucoma is open-angle or closed-angle, it is the chronic nature of the disease that needs to be addressed when providing long-term eye care in a low-resource environment.

Diagnosis

Glaucoma can present in many ways, but in the most classic form, intraocular pressure is higher than 21 mmHg (with 10-21 mmHg reference range), there is loss of visual field (first peripheral vision and, later, central vision), and the optic nerve appears excavated (i.e. changes occur in the shape of the optic disc at the back of the eye). A family history of glaucoma is highly important, as are risk factors such as "diabetes mellitus, African descent, and ocular injury" (Schwab 2007:103). Diagnosis of glaucoma can be made using relatively simple tools and techniques: the IOP can be measured using a tonometer, finger counting and cross-confrontation visual-field testing can be used to check for peripheral visual field loss, and a slit lamp or direct ophthalmoscope can be used to assess the changes in the optic nerve. Such tools are used at Unite For Sight outreaches in Ghana, but not in Chennai, India, where glaucoma is diagnosed by the ophthalmologist at an eye clinic, not by the optometrist during the outreaches (because only ophthalmologists are permitted to make a glaucoma diagnosis in India; see Results for more detail). In both Ghana and India, Unite For Sight outreaches are run by optometrists; the ophthalmologists practice only in the clinics.

Treatment

While loss of vision due to glaucoma is typically irreversible, Schwab (2007:109-112) summarizes the medical and surgical methods available to manage and prevent further vision loss. Medications (typically available as either eye drops or ointments) can reduce eye pressure by two mechanisms. One type (including epinephrine, beta-blockers, and carbonic anhydrase inhibitors) reduces intraocular pressure by decreasing how much

fluid the ciliary body produces. Each of these three drugs has its own drawbacks. For example, epinephrine increases heart rate, stings the eye, and requires refrigeration; beta-blockers slow the heart rate, may exacerbate asthma, and are expensive for long-term use; carbonic anhydrase inhibitors cause serious long-term side effects such as kidney stones. A second type (including pilocarpine) reduces intraocular pressure by improving aqueous outflow through the trabecular meshwork; pilocarpine has uncomfortable side effects such as headaches, dim vision, and nausea. Other medications such as alpha agonists and prostaglandin analogs have a combination of mechanisms for lowering intraocular pressure, but are expensive and may require refrigeration. Thus, medical treatment becomes very problematic, especially over the long term with monthly eye drop prescription costs, periodic check-ups, side effects, and lack of access to medication for various reasons. Access to refrigeration is an additional problem in low-resource environments.

Surgical management of glaucoma is carried out by filtration surgery, which is used to reduce the intraocular pressure permanently, to protect whatever vision is left. Filtration surgery has two components or approaches– a trabeculectomy (removing some of the blocked trabecular meshwork, creating a small hole or fistula to drain fluid) and glaucoma tube surgery (inserting a drainage tube in the anterior chamber to shunt fluid to an external reservoir). An iridectomy (creating a small fistula in the iris) can also be performed as a treatment for acute angle-closure glaucoma. Trabeculectomy and iridectomy can be "performed under local anesthesia using cataract instruments," but, for reasons unclear, "filtration operations frequently fail in darkly pigmented people [as the]

fistula closes by scarring and then ceases to function" (Schwab 2007:113). As such, "patients who are of African descent may require antifibrotic agents when undergoing [first-time] filtration surgery" – i.e. antimetabolite medication becomes necessary to maintain the fistula, thereby making the usefulness of a surgical approach limited when working with patients in certain low-resource environments (Lee et al 1999:385). Additionally, glaucoma tubes for glaucoma tube surgery are expensive, not readily available, and can cause significant late complications; glaucoma surgery requires a high level of training and high rate of post-surgical follow-up (compared to cataracts). Thus, the main method of treatment in low-resource environments is medical rather than surgical.

Unite For Sight and Partner Clinics

To understand the context of the research, information on Unite For Sight and its partner clinics is necessary. Unite For Sight (UFS) is a non-profit organization based in the United States, founded in the year 2000 by a Yale University undergraduate, Jennifer Staple-Clark. The aim of the organization is to improve eye care access to patients in developing countries. The organization began with several years of fundraising via growing numbers of university chapters throughout the United States, established from 2003 onwards. With the funding gained through 25 university chapters, Unite For Sight began partnering with already-existing clinics in developing countries – the first one in Accra, Ghana in 2004. As fundraising continued, more partnerships were established, allowing for greater numbers of patients to be served. Today, such partner clinics – established prior to UFS partnership and owned and run by local staff and local

ophthalmologists in Ghana, India, and Honduras – have served over 1.6 million patients (UFS 2013b). Unite For Sight prides itself on working with local communities and clinics and creating sustainable partnerships that are well regarded in the global health community. This research is based on volunteering carried out in clinics in Ghana and a clinic in Chennai, India.

Unite For Sight helps the eye clinics treat more patients by subsidizing the cost of eye surgery for patients living in poverty, who would otherwise not be able to pay for eye surgery. In Ghana, UFS subsidizes cataract and pterygium[1] removal surgery; in Chennai, India, UFS subsidizes cataract surgery. Surgery patients are located during outreaches, which will be discussed shortly. In addition to subsidizing eye surgeries, Unite For Sight accepts volunteers from the US and other countries year-round to assist the clinics' staff in taking patient histories and doing simple visual acuity screening. Such volunteers also fund-raise prior to their volunteer experience abroad ($1800 per trip), and it is this fund-raising that subsidizes the surgeries. Volunteers also donate and bring abroad 600 eye glasses as part of their volunteering. Additionally, a volunteer must observe and sign that he or she has observed any surgery that is sponsored by Unite For Sight, to verify that every surgery that is sponsored is carried out. This ensures that the funds for sponsored eye surgeries are used appropriately.

In order to find patients who would benefit from eye surgery that Unite For Sight would subsidize (in addition to providing eye glasses at a token fee), each eye clinic runs outreaches to high-need rural or urban areas, anywhere from 1 hour to 8 hours away from

[1] Pterygium is tissue that grows over the surface of the eye, eventually obscuring vision. It occurs in people who work in dusty conditions and in the outdoors with high UV exposure.

the clinic (UFS 2013a). The clinics are the ones who determine if a community is high-need and the outreaches are based on clinic-established connections with community leaders/liaisons who publicize and promote the outreaches. (Of course, this makes the data in this study highly biased towards looking at only these outreaches.) On the day of the outreach, the clinic staff (composed of at least one optometrist and several clinic employees) and foreign volunteers arrive at the outreach village and set up a screening process to check for everything from refractive error to the presence of cataracts and glaucoma. The community liaisons help facilitate the outreach process.

The structure and extent of the comprehensiveness of the outreaches varies by location and between countries. Since the community liaisons will have publicized the outreach, anywhere from 50 to 500 people arrive at the outreach site, and the outreach team spends the day screening the patients. For simple conditions such as refractive error or eye allergies, glasses and eye drops are sold. Glaucoma eye drops are sold in Ghana, but are not sold at Chennai outreaches because the optometrist does not diagnose glaucoma during outreaches. While the glasses are donated by volunteers and sold at a token fee (to ensure that patients value and use the glasses), medicines such as eye drops are sold at a market price.

From a group of several hundred screened, a dozen people may require eye surgery (for cataract and pterygium in Ghana, and cataract in India). Such patients are given an appointment slot at the partner eye clinic for a Unite For Sight-subsidized surgery several weeks away; the community liaisons coordinate transportation to the clinic for the patients coming from the same location (the patients typically pool together

money for a shared mode of transportation). While many patients decide to get surgery, there are also many who decline for various reasons. Similarly, some patients decline to purchase glaucoma or other eye medication or glasses. Barriers to glaucoma care will be presented through the research done in this eye care setting.

Theoretical Insight

Two main theories inform the analysis in this thesis. The Health Belief Model looks at individual-level variables that impact health care decision making, and the Socio-Ecological Model connects the individual to larger social structures. It is at the successful interaction between individual and social structures that glaucoma prevalence is best understood, diagnosis emphasized, and treatment carried out.

Health Belief Model

The Health Belief Model is a psychologically-driven theory that predicts an individual's behavior related to health care decisions. The main assumption of the theory is that individuald will evaluate healthcare choices based on how likely they perceive themselves to benefit (or prevent harm) by making certain healthcare decisions. The core component of the Health Belief Model is the patient's *perception* of their condition. Patients negotiate a healthcare decision according to four factors: perceived severity of a condition, perceived susceptibility to a condition, perceived benefits from obtaining diagnosis or treatment, and perceived barriers to obtaining diagnosis and treatment.

Mansberger et al (2103) applies these constructs of the Health Belief Model to the treatment of glaucoma, particularly eye drop adherence (sometimes referred to as compliance, although adherence suggests a more amicable and cooperative relationship

between the patient and health care provider). Under the Health Belief Model, a patient with glaucoma will adhere to treatment if "he or she places a high value on his or her current level of vision and also believes that ocular hypotensive medication will prevent further vision loss" (Mansberger et al 2013).

On the component of perceived severity, patients form an opinion of how serious glaucoma and its consequences are; patients must perceive that they could go blind from glaucoma in order to seek an eye checkup/diagnosis and to maximize their likelihood of adhering to treatment.

On the component of perceived susceptibility, patients form an opinion of how likely they are to develop glaucoma; patients must understand their family history and make a decision to seek a diagnosis and treatment based on this history.

On the component of perceived benefits, patients form an opinion of how helpful an eye checkup/diagnosis is and decide if they think eye drops will be effective in lowering their chance of going blind from glaucoma; patients must have the perception that an eye checkup is a good idea and that eye drops are one of the most effective ways of lowering eye pressure and preventing blindness from glaucoma.

On the component of perceived barriers, patients form an opinion on the difficulty and cost of obtaining diagnosis and treatment; patients must value the diagnosis and eye drops highly enough to make tradeoffs against other financial, time, and psychological demands or constraints (Mansberger et al 2013: Table 1). According to the Health Belief Model, it is when all these perceptions are aligned that diagnosis and long-term,

successful treatment occurs. Thus, any deviation in these perceptions presents a barrier to glaucoma diagnosis and treatment.

Socio-Ecological Model

While the Health Belief Model is patient-centered and primarily psychological in nature, the Socio-Ecological Model (SEM) helps us make the connection between the patient and the external environment. Certainly, patient perceptions are not formed in a vacuum and are influenced by external layers of society. Different formulations of the Socio-Ecological Model have identified different layers in the Model. At its most basic, the Socio-Ecological Model looks at the relationship of the individual to other individuals, the relationship of the individual to the community, and the relationship of the individual to society. Other variants of the SEM look at individual-level, interpersonal-level, organizational-level, community-level, and policy-level variables and how these impact health. The SEM has been applied to everything from violence to colorectal cancer prevention (Centers for Disease Control and Prevention 2013).

Applying the Socio-Ecological Model to glaucoma, the individual level represents many of the facets of the Health Behavior Model. This includes an individual knowing about glaucoma and pursuing a diagnosis and treatment, and having access to such diagnosis and treatment. The interpersonal level represents patient interactions with eye care professionals, who inform the patients about glaucoma, suggest and carry out a glaucoma screening, and put the patients on the way to long-term treatment. Other interpersonal-level actors include other patients who have or do not have glaucoma, and

family members with glaucoma; such actors can influence the patient to seek a diagnosis and treatment.

The organizational level represents larger organizational attempts at addressing glaucoma. In a non-profit such as Unite For Sight and its partner clinics, this involves an organizational awareness of glaucoma, employing professionals who can diagnose and treat glaucoma, distributing and subsidizing glaucoma medication, and emphasizing glaucoma diagnosis and treatment as one of its organizational goals. Additionally, organizations can be leaders in disseminating knowledge and awareness about glaucoma prevalence, to reinforce the importance of diagnosis and treatment. At the community level, schools, community groups, media, local leaders, and religious institutions play a role in disseminating information about prevalence, importance of diagnosis and treatment, so that people can make informed health decisions per the Health Behavior Model. Lastly, at the policy level, local and federal/national governments and international institutions can provide funding, research emphasis, and policy emphasis via national health campaigns, which can provide information about prevalence and encourage diagnosis, and provide treatment by creating the appropriate healthcare infrastructure. Thus, the Socio-Ecological Model and the Health Behavior Model work together, integrating the individual and the external or environmental requirements for successful glaucoma diagnosis and treatment.

Barriers to Glaucoma Care

It is important to conceptualize what one means by successful glaucoma care, and where such barriers to care can occur. This thesis will look at barriers to care as occurring

at three distinct levels: 1) a misunderstanding of the prevalence, 2) a lack of diagnosis, and 3) a lack of adequate long-term treatment. These three levels interact with four categories of barriers – psychological, economic, structural, and socio-cultural, each of which is inseparable from the other three – and these barriers are experienced by both the patient and the eye health care provider/program. The structural barriers include procedural and medical system issues that prevent proper glaucoma prevalence assessment as well as lack of proper diagnosis, tracking of patients, and proper disease management from the glaucoma care provider position. The economic barriers of providing glaucoma care occur from both the patient perspective of purchasing and managing medication costs and follow-up visit costs, as well as the provider perspective of providing such services. The psychological barriers affect diagnosis, follow-up, and eye drop adherence for glaucoma patients, particularly in resource-limited settings. The socio-cultural barriers of providing glaucoma care occur at the intersection of patient and provider and include language as well as cultural barriers related to perceptions of health, disease, and proper treatment. For each of these components, proposed as well as successfully and unsuccessfully implemented solutions exist and will be analyzed – thus, something that is a barrier in one location may have been addressed in another location. It is extremely important to keep in mind that each one of these components rarely occurs separately, and it is difficult to divide up barriers as strictly structural, economic, psychological, or sociocultural. Thus, each aspect will be analyzed always in relation to the three others.

Structural Barriers

The structural barriers to care are predominantly oriented towards the provider, which can be conceptualized on both a macro level – of the government or international institutions as providers of care as well as research studies on glaucoma – as well as the micro level – of individual care providers, particularly non-profit organizations that work in low-resource environments. These two halves must be "viewed in the context of a health care system" and can include "public, private, civil society as well as emerging models of social entrepreneurship and public private partnership" (Damji 2013:3). Structural barriers exist at every level and have effects on the understanding of prevalence, proper diagnosis, and proper treatment.

One barrier to understanding glaucoma prevalence and successful diagnosis and treatment is that many international organizations geared towards improving eye care are not focused on glaucoma. For example, international efforts such as VISION 2020 focus on five conditions: cataract, trachoma, onchocerciasis (river blindness), eye conditions in children, and refractive error and low vision. Diabetic retinopathy is to be added to the priority list because of the increase in diabetes in developing countries, whereas glaucoma ambiguously "remains on the agenda due to difficulties in its early diagnosis and frequent necessity of life long treatment" (WHO 2004:1). Thus, glaucoma seems to be secondary to other, more easily managed and curable eye conditions.

In terms of understanding prevalence, the large emphasis on infectious diseases in developing countries overshadows chronic, non-communicable conditions such as glaucoma (Bowen 2011). A meta-analysis carried out by Kyari et al (2013) found a total

of nine population-based studies (PBS) of glaucoma in Sub-Saharan Africa, and "three were classified as good, one was satisfactory, and five had incomplete reporting" (Kyari et al 2013). Kyari et al (2013) also found four glaucoma prevalence studies in African-derived populations living outside of Africa, and fifty-five publications looking at blindness and visual impairment in Sub-Saharan Africa, with glaucoma not mentioned or not clearly defined. Thus, Kyari et al (2013) concluded that "there are few PBS (population-based studies) data that provide estimates of any/all types of glaucoma in Sub-Saharan Africa, and only four provide reliable estimates."

Additionally, an understanding of prevalence on the part of the patient is necessary before diagnosis can be pursued. A very low percentage of patients in developing countries are aware of what glaucoma is, not to mention its risk factors and heritability. A study at ophthalmic outreaches in Southwestern Ethiopia, for example, found that only 2.4% of outreach patients knew about glaucoma (Tenkir et al 2010). Similar results are found in Ghana, and will be discussed later. Such low results illustrate a need for public health campaigns and education in schools and other locations geared towards glaucoma prevalence (including an awareness of risk factors and heritability), diagnosis, and treatment.

Even if prevalence is understood, there are structural barriers at the level of diagnosis and treatment, suggestions for which have most recently been elucidated in The International Centre for Eye Health's (ICEH's) *Community Eye Health Journal* Vol. 25 Issues 79 and 80, 2012. One barrier is the simple lack of healthcare professionals who can diagnose glaucoma, something that can be ameliorated with "people working in

primary health care [who] have a major role to play in the counseling of patients and their relatives who are also at risk" and "mid-level personnel with good training and supervision [who] can help by taking regular measurement, capturing and transferring information and images, and making timely referral of patients according to agreed clinical guidelines and protocols" (ICEH 2012:42). Such an approach can circumvent the problem of the limited number of trained eye care professionals, and this can be accomplished with the aid of community liaisons and emphasizing treatment provided by optometrists rather than ophthalmologists.

Once diagnosis is achieved, structural issues at the level of treatment arise. Since glaucoma requires long-term treatment with regular follow-ups, it is necessary to improve patient experiences and the level of care during follow-up visits (not to mention reduce geographic/transportation barriers to follow-up visits): "treat patients on a strictly first-come, first-serve basis… improve record keeping and filing systems… and reduce waiting times" (ICEH 2012:45).

To summarize the structural barriers for glaucoma care:

> Glaucoma care needs to be given high priority in Vision 2020 programs in Africa. Many questions remain unanswered and there is a need for further research in glaucoma in SSA [Sub-Saharan Africa] in all aspects especially epidemiology and clinical care and outcomes involving randomized controlled trials. Genetic and genome-wide association studies may aid identification of high-risk groups. Social sciences and qualitative studies, health economics and health systems research will also enhance

public health approaches for the prevention of blindness due to glaucoma (Kyari et al 2013).

Structural Barriers in Ghana and India

Barriers to understanding prevalence occur because there is limited research carried out on the issue of glaucoma prevalence. Unfortunately, the single Ghana-specific study identified by Kyari, et al (2013) was classified as "incomplete", while only four carried out in the entirety of Sub-Saharan Africa were considered good or satisfactory. Clearly, the lack of research geared towards glaucoma prevalence, particularly geographic distribution (as prevalence ranges from 1.02% in Nigeria to 8.5% in Ghana), is one of the large structural barriers that then make diagnosis and treatment difficult (Kyari et al 2013). Not many more population-based studies have been carried out in India – George et al (2007) identified five such studies in several rural and urban locations around India, not enough to represent the 11.9 million people who have glaucoma in the large and ethnically diverse country (George et al 2007).

In terms of raising awareness on a large scale, the First African Glaucoma Summit was held in 2010 in Ghana, as the World Glaucoma Association "has decided to make Glaucoma in Africa the focus of its international education effort, and the meeting in Ghana is a first step in that direction" (WGA 2013). The Ghanaian government, via the Ghana Health Service (GHS), has likewise "over the years initiated various programs aimed at improving the eye care system in the country. The month of January has, therefore, been set aside by the World Glaucoma Association to promote education on the disease" (Al-Hassan 2013). In India, World Glaucoma Day was most recently commemorated by the Vidarbha Opthalmic Society and several articles have been

published in the Times of India (Gwalani 2014). This suggests some attempts by international organizations, the Ghanaian government, and Indian ophthalmic societies and news outlets to spread awareness about glaucoma in the population.

In terms of the patient's awareness of the prevalence of glaucoma, a study in Ghana found that 3.5% of 1775 community members were aware of glaucoma, 0.8% understood it, and 1% knew that it could be hereditary (Ntim-Amponsah et al 2004a). In India, a study found that 98.5% of rural patients in one study were unaware of glaucoma (Vijaya et al 2005). Thus, patient education is equally important in India and in Ghana. Without knowledge that glaucoma is a threat to eyesight, there is a limit to how well care can be provided. Glaucoma may then often only be diagnosed once the patient comes to an eye care professional for a pair of reading glasses or other eye problems not related to glaucoma, and who might already be experiencing advanced visual field loss. In Ghana, 96% of rural and 76% of urban patients diagnosed with glaucoma already had an advanced case of the condition (Bowen 2011:17). Structural barriers in access to education as well as access to eye care create such discrepancies in awareness and outcomes.

Another powerful structural limitation is the number of eye care professionals able to treat glaucoma. In Ghana, there are two ophthalmologists for every million people and, in India, there are nine ophthalmologists for every million people; this can be compared to eighty-one for every million people in the United States (ICO 2013). Additionally, ophthalmologists are typically located in urban areas, with 70% of Indian

ophthalmologists practicing in urban areas, although the vast majority of the population lives in rural areas (De Souza et al 2012).

Looking at optometrists, there are "about 50 optometrists for a population of nearly 20 million" in Ghana, which translates to approximately 0.25 per 100,000 (Thompson 2002). This can be compared to 7.83 optometrists per 100,000 in the US (The New York Center for Health Workforce Studies 2006:132). In India, optometry training varies, but the more prevalent two-year courses in optometry do not allow the optometrist license to diagnose glaucoma and provide comprehensive care; four-year education programs are just becoming established and these allow for more comprehensive treatment, including glaucoma diagnosis (De Souza et al 2012). This profound shortage of eye care professionals who can diagnose glaucoma in Ghana and India makes structural inadequacies of the system quite acute. Patients have little face-to-face time with eye care professionals, who have little time available to educate patients. Other routes to educating, diagnosing, and treating patients (such as the use of rurally-located community health workers) are being tried by organizations such as the Carter Foundation, which is "training a corps of healthcare workers throughout seven universities in Ethiopia, so that even people in the most remote areas will have access to treatment" of onchocerciasis (river blindness) (Poole 2007). Similar efforts can be attempted for glaucoma.

Economic Barriers

Unlike structural barriers, which tend to be provider-oriented, the economic barriers to glaucoma care can be seen from the perspective of the patient as well as the

perspective of the provider/program, at the levels of an understanding of prevalence, access to diagnosis, and access to treatment. In this section, since the research was done on a small scale and in the context of the non-profit sector, the provider is defined more narrowly as non-profit organization that is pursuing healthcare benefits for the community, while also keeping an eye on costs.

Obtaining a glaucoma diagnosis is crucial – as previously mentioned, 50% of patients in any community remain undiagnosed, while 90% remain undiagnosed in limited-resource environments (the particular study taking place in India) (Nayak et al 2011). While lack of diagnosis can occur because of psychological, socio-cultural, and structural reasons, the literature also unanimously agrees that: "some patients do not have access to professional eye care because of insufficient financial resources or no means of transportation" (Nayak et al 2011).

For community-based eye care organizations, "although the office-based identification of glaucoma can permit the early detection and treatment of the disease and can be cost effective, [glaucoma screening] has yet to prove a cost-effective strategy in a community setting" (Picciani et al 2011). When evaluating usefulness of glaucoma screenings, it is useful to look at the examination cost per case detected. The Nettie Taylor Project in Philadelphia, for example, used low-paid and volunteer staff and low-cost equipment to test for glaucoma in 2000 patients. Twenty 2-hour sessions led to a diagnosis rate of 10% with a cost of $140 per diagnosis, and using more expensive technology would have increased the cost to $290 to $465 per diagnosis. To reduce the costs per patient, "more targeted screenings within populations [who are] both at high

risk for glaucoma and likely to benefit from earlier treatment might be cost-effective." The Nettie Project, therefore, focused on elderly African Americans, which "helped increase the screening yield" but was also plagued with a very low follow-up rate (Picciani et al 2011). Thus, glaucoma screening is a cost-effective tool if targeted specifically to certain high-risk populations who will have access to continued treatment. Such targeting, of course, rests on an understanding of the prevalence, which is often poorly understood due to economic and structural barriers that make such research difficult (Picciani et al 2011).

Moving on to treatment, in a yearlong study carried out in the Netherlands healthcare system, costs for glaucoma treatment varied for several reasons. First, depending on the severity of the diagnosis, a diagnosis of ocular hypertension without other symptoms was less costly than a complex diagnosis of glaucoma. Patients with ocular hypertension had an average of 2.43 visits to the ophthalmologist per year, whereas those with advanced glaucoma had an average of 3.74 visits per year, and the mean cost per patient was $280 and $559, respectively. Patients with no changes in medication therapy paid a mean of $347 for their care, whereas those with more than three adjustments paid $1765 for their care. Following the diagnosis, the major determinants of these costs were thus the number of outpatient visits to the ophthalmologist, medication costs, and the type of hospital frequented (general or academic, which was more expensive) (Oostenbrink et al 2001). A similar study in the US found that "the average direct cost of glaucoma treatment [also partially covered by Medicare] ranges from $623 per year for patients with early-stage glaucoma to $2511per

year for end-stage patients" and that "medication costs composed the largest proportion of total direct costs for all stages of disease (range 24%-61%), even while controlling for adherence rates" (Lee et al 2006). Thus, physician and medication costs are the major economic drivers of barriers to glaucoma treatment, and insurance is a necessity when paying for glaucoma care. Additionally, glaucoma that is being treated at an early stage has much lower costs associated with it, showing the importance of early diagnosis from an economic perspective.

Minimizing cost of providing care is of utmost importance to a non-profit provider. Screening should be "for eye disease in general, not just glaucoma" and "not only should populations be carefully targeted based on disease prevalence, but [also] on the likelihood that subsequent care will be delivered" (Picciani et al 2011). To manage equipment costs, the "skills of someone trained to evaluate the optic nerve to make a diagnosis, especially in cases of early disease" should be used, rather than more expensive and highly specific equipment and tests that are not useful for diagnosing other eye diseases (Picciani et al 2011). Thus, organizations should seek to be comprehensive, maximize the use of simple technology, and provide diagnosis early-on to those likely to get follow-up treatment to minimize the economic costs of running their programs.

Economic Barriers in Ghana and India

The economic barriers to care are much more pronounced in low-resource environments, and barriers occur for the patient as well as for the provider at every level – of understanding prevalence, of getting a diagnosis, and of obtaining treatment. The very lack of studies on prevalence across Ghana and India suggests a variety of barriers

to understanding glaucoma, and the economic barriers to such wide-scale research are certainly present.

Patients in low-resource environments have limited access to glaucoma diagnosis because of patient economic barriers to obtaining a comprehensive eye screening, including barriers such as transportation costs, screening costs, and opportunity costs, as well as a lack of trained eye care professionals. Thomas (2012) concludes that it is best to approach diagnosis in developing countries on a case-detection basis, which screens any patient presenting at an eye clinic for an eye exam for glaucoma. Thomas (2012) opposes population-based screening as a feasible way to diagnose in low-resource environments, as "developing countries do not have the requisite infrastructure to categorize and follow up test positives on various screening tests, let alone treat the true positives and certainly not enough to repeat the process on a regular basis" (Thomas 2012). However, even case detection is difficult in a resource limited setting because of the previously mentioned "excessive workload" experienced by the few eye care professionals and "the cost of slit lamps, applanation tonometers, and diagnostic lenses" (Thomas 2012). Thus, the economic barriers to diagnosis for both the patient and the provider are severe in resource-limited environments.

In terms of economic barriers to treatment from the perspective of the patient, not only are medicines not readily available, but they are also expensive relative to the income of the patients – "even generic beta blockers and pilocarpine may cost more per day than basic necessities such as food" (Egbert 2002). Patients in a British study were "untreated for short periods, having run-out of drops, failing to re-order drops or having

experienced problems obtaining new drops before current bottle expiry" and also experienced issues of "keeping drops cool [i.e. refrigerated]"; prescription costs were a particular issue (Lacey et al 2009:929). Certainly, such limitations occur in Ghana, as the per capita annual income is $1550 in current US dollars, so "patients prescribed medications will use them only until the more basic demands of daily living re-assert themselves" (World Bank 2012; Thomas 2012). In addition, in Ghana, geographic barriers to care (in terms of travel time and difficulty) as well as the costs associated with care with the few eye care professionals creates the conditions for an "extremely poor rate of follow-up after treatment (19% at six months)" (Verrey et al 1990). To ameliorate the financial burden of health care, a National Health Insurance Scheme (NHIS) was established in 2005 and covers eye care in Ghana (including subsidizing several glaucoma medications); the yearly premium ranges from 20-25 Ghanaian cedis (about 10-12 USD), but only a maximum of 18% of the population has actively enrolled in the program in any given year. The main reason for not joining the scheme (for 77% of individuals surveyed) was the inability to pay the NHIS premium, although all tax-paying Ghanaians fund the NHIS system through a 2.5% insurance levy added to the VAT (Oxfam International 2011:26). Thus, gaining financial help to pay for glaucoma treatment is difficult, even with an existing national health insurance program.

In India, 69% of ophthalmologists work in the private and NGO sector, while 31% work in the government sector (Murthy et al 2004). Thus, while government-run eye facilities exist, the majority are in the private sector, which is highly fragmented, concentrated in urban areas, and costly. A study in rural south India showed that 78.2%

of patients reported a lack of funds and 70% reported a lack of time to go to the eye doctor; interestingly, 34.1% of patients diagnosed with glaucoma had reported going to a hospital for eye care in the past, and 15.9% diagnosed with glaucoma had even visited an eye doctor before (Robin et al 2004). Thus, while eye care is available throughout various government hospitals all across India, the quality and cost of such care seem to be barriers to getting a glaucoma diagnosis and treatment. In a similar study in Tamil Nadu, 28% of rural patients self-reported taking an hour or more to get to a pharmacy and younger patients had more problems paying for their medication, with 21.8% of all patients self-reporting financial difficulty. Such economic and structural barriers contribute to poor diagnosis and low adherence rates to glaucoma treatment (Sleath et al 2009).

Psychological Barriers

Psychological barriers occur primarily from the perspective of the patient rather than the provider. There are psychological barriers to care at the level of understanding prevalence, seeking diagnosis, and maintaining treatment. The Health Belief Model serves as a good illustrator of this issue, as it suggests that people must first perceive a disease to be important and relevant to them in order to seek diagnosis and then treatment (Ogden 2007:23-24). Without proper education and lack of an understanding of prevalence and the heritability of the disease, glaucoma diagnosis and treatment does not occur.

There is an age distinction in the psychological perceptions of prevalence and susceptibility to glaucoma. In a qualitative study carried out by Lacey et al (2009) in the

NHS system of Great Britain, glaucoma patients who tended to be younger (classified in the study as under 60 years of age, as Western literature mistakenly yet universally considers glaucoma to be an old-age disease) "discussed concern about life-long treatment and a feeling of isolation in clinics when surrounded by older patients" and often felt "treated differently by staff" (Lacey et al 2009:930). Such psychological barriers certainly affect how younger people perceive prevalence and seek diagnosis and treatment for their glaucoma. The misunderstanding of the prevalence is also a structural issue, however, that relates to a lack of education and a lack of research emphasis on a particular issue.

Once a patient is diagnosed, the key way to prevent vision loss from glaucoma is by adhering to medications, particularly eye drops, which prevent intraocular pressure from increasing. Psychological barriers strongly relate to eye drop adherence. In Lacey et al (2009), patients elucidated some of the barriers they felt towards success of their glaucoma care. Patients lamented a lack of down-to-earth, face-to-face education (as opposed to using leaflets), suggested that "doctors emphasize the consequences of poor adherence, drop application techniques, and advice about application schedules," and hoped that more education would occur throughout follow-up visits (Lacey et al 2009:927). Thus, lack of education can be seen as a psychological barrier to proper adherence.

Eye drop technique was a particular source of concern and uncertainty for patients, who either tended to become comfortable with eye drops over time, or tended to never become accustomed to them. Patients suggested that better eye drop administration

education is absolutely crucial, as most tended to rely on typically conflicting information provided on the eye drop packaging, the Internet, and other sources. Many would have liked "their practitioner to check their current technique" (Lacey et al 2009:929). Of course, this factor intersects with the structure of the medical system, and the amount of time medical professionals have available for each patient, as well as the general education level of the population regarding eye care.

Another psychological factor is a lack of faith in eye drop efficacy. Patients frequently had negative feelings about eye drops' effectiveness and also disliked the negative side effects. However, some patients did continue to apply eye drops, despite the unpleasant side effects, because they already had symptomatic vision loss. Some patients "desired more regular feedback about drop efficacy [such as progression of disease during follow-ups]," which they felt would provide them with "greater faith for adherence" (Lacey et al 2009:929).

Another simple yet very crucial component of treatment elucidated by Lacey et al (2009) was forgetfulness. Twenty-two out of twenty-four patients admitted to forgetting their eye drops at some point, and typically consisted of either frequent/occasional or rare forgetters, who would not be concerned or would become very concerned about missing their dosage, respectively. Most used some kind of schedule to apply their drops, and there was an increase in forgetfulness as the eye drop schedule became complicated.

Psychological Barriers in Ghana and India

In Ghana, the age distribution of glaucoma is unique in that glaucoma has a much earlier onset; this early onset is seen at outreaches and is documented by various studies (Kyari et al 2013). Problematically, the expectation that glaucoma is an old-age disease is

not true in Ghana. In addition to a lack of awareness of prevalence, the age factor poses a psychological barrier of perception of susceptibility towards disease, as explained by the Health Belief Model. About 6% of the 30-34 age category has glaucoma, and this steadily increases to 7.3% in the 50-54 age category, and is as high as 27.1% in the 75-79 age category (Ntim-Amponsah et al 2004b:Table 2). This distribution suggests that young people do get glaucoma, and thus have to overcome the psychological barriers of getting such a (typically asymptomatic and thought to be an old-age) diagnosis early in life.

When looking at psychological factors in relation to treatment, the problem posed by patients in Lacey et al (2009) on the need for more face-to-face time with physicians intersects with the structure of the medical system. Unfortunately, the amount of time medical professionals have available for each patient is extraordinarily limited in low-resource environments. As discussed previously in the text, there is a profound shortage of eye care professionals in Ghana and India, which makes the face-to-face time problem extremely acute and education ability of such eye care professionals extraordinarily limited, exacerbating the psychological barriers to care. In India, seemingly simple issues such as difficulty opening or squeezing the bottle, and not knowing how to apply eye drops, led to increased non-adherence among younger glaucoma patients (Sleath et al 2009).

The issue of faith in eye drops is particularly acute in low-resource environments, where efficacy may be related to an expectation of improvement in vision (when no such improvement is possible with glaucoma) due to a lack of education about glaucoma. Glaucoma patients at outreaches interact with cataract patients who become cured of their

cataracts; lack of such a cure for glaucoma may cause a loss of faith in eye drops. Patients may additionally favor glasses over eye drops, since glasses are perceived to "fix" vision. The follow-ups that would re-emphasize adherence to medication do not occur because of economic, structural, and socio-cultural barriers. Also, the belief that eye drops and other treatments are unnecessary for asymptomatic conditions is highly prevalent in low-resource conditions. Bowen (2011:18) studied this issue in Ghana and found that "while talking to glaucoma patients, more than half expressed feeling no need to seek care from an eye doctor until they noticed a problem." This psychological barrier intersects with socio-cultural beliefs about disease, but such beliefs are quickly changed when "after being diagnosed and receiving glaucoma treatment, patients then saw the value of preventive ophthalmologic care." One patient who is a pastor "invites health professionals to speak to his congregation about basic healthcare and the need for certain kinds of preventive care" (Bowen 2011:18).

While forgetfulness seems to be a universal, patients with lower levels of education (partially stemming from little face-time with the eye care professional) may underestimate the importance of using eye drops and may thereby have a higher tendency to forget. Also, patients who are treated for other conditions (such as allergies or pterygium) in addition to glaucoma may find treatment schedules unmanageable and may forget various doses of various medications. Additionally, patients who are not educated about the relative importance of their glaucoma diagnosis (versus their allergy diagnosis, for example) may treat all the conditions as equal and may forget glaucoma drops at the same rate as other drops.

Socio-Cultural Barriers

Socio-cultural barriers occur in relation to patients and providers, often at the intersection of the two. There are countless socio-cultural barriers that can be identified, and only a few will be mentioned here.

Morris, et al (2009) carried out a qualitative study that examined the social barriers to health care experienced by refugees resettled to San Diego from countries such as Somalia, Russia, Iraq, and Afghanistan. Apart from the economic and structural barriers to care (such as transportation and healthcare costs), language and communications barriers were strongly present. "Language barriers exist not only during interactions between doctors and patients but at every level of the health care system, from making an appointment to filling a prescription… [and would] lead to refugees either utilizing health care services only when they are very sick, or not at all" (Morris et al 2009:533). Such language barriers are certainly possible in resource-limited settings where many languages are spoken and the languages spoken by the (few) eye care professionals differ from that of the patient. When using interpretation services to bypass the issue of language, many "health care providers perceived problems with relying on family members, including misinterpretation and confidentiality issues" (Morris et al 2009:534).

Another component of the study found that "culture directly affected refugees' concept of prevention services, independence, expectations of care and stigma around health care – all of which influenced their health care choices" (Morris et al 2009:535). Patients who were refugees were "not fully accustomed to the idea of preventive care"

and they had "expectations of western medical care [that included] specific behaviors of doctors, curing chronic diseases instead of managing them, and fast care by clinics" (Morris et al 2009:535). Gender came in to play, as women from some refugee groups felt uncomfortable with health care providers of the opposite sex. Patients in the Lacey et al (2009) study encountered socio-cultural barriers to adhering to eye drop regiments because of the "difficulties in finding a convenient location (often due to embarrassment)," suggesting a certain discomfort of applying eye drops in social situations and the stigma of having an illness. Some health care providers also spoke of "refugees relying on homeopathic treatments and spiritual healers [which] refugee participants did not view as a barrier to accessing medical services here in the US. Instead, refugee participants noted that they use some cultural remedies but do not view it as a replacement to western care" (Morris, et al 2009:525).

Socio-Cultural Barriers in Ghana and India

While Ghana's official language is English, there are also nine local languages that Ghanaian students can study in school and which are used in daily life, and the most widely spoken local languages are Twi, Ga, Dagomba, Akan, and Ewe (Ghana Embassy 2013). Similarly, while English is an official language in India, patients from each state speak several languages; patients in Tamil Nadu, for example, speak almost exclusively only in Tamil rather than Hindi. In short, various parts of the each country speak different languages, creating a language barrier if the patient is one part of the country and the provider is from another; however this barrier may be overstated, since most locations were frequented by patients from roughly the same area and language background. Additionally, the ability to speak English (which providers in Ghana and India speak

almost universally) varies significantly with education levels, so that patients who are most in need of care may encounter the greatest language barrier.

The socio-cultural barrier related to preventive care is also present in Ghana and was mentioned in a previous section on psychological issues, as "more than half of glaucoma patients expressed feeling no need to seek care from an eye doctor until they noticed a problem" (Bowen 2011:18). Expectations of medical care in resource-limited environments is not particularly high, as patients in a study in nearby Togo found that "56.1% [of patients] were not confident in the local doctors for the treatment of glaucoma," and this serves as a worrying barrier to obtaining care (Balo et al 2004).

On the issue of gender, a study by Gyasi et al (2010) found that "despite the higher preponderance of male patients with POAG [primary open-angle glaucoma], the females were more than twice as likely to become blind from the disease. These findings reflect the socio-cultural aspects of male dominance in a many societies where men control the family wealth and are more likely to have the upper hand in assessing [the value of] 'pay-for-health care' services." Thus, while males tend to have glaucoma at a slightly higher rate than females, female blindness is more prevalent from glaucoma. This observation is an example of a socio-cultural attitude towards women that reduces the access to glaucoma care that women receive, thereby limiting their chance at maintaining sight.

Similar to the situation of refugees in San Diego, many Ghanaians access traditional healers for their healthcare needs. Unlike optometrists and ophthalmologists, which are in short supply, there are traditional healers in nearly every community who

"often know their patients personally, and have cultural history and societal structure on their side." While there are instances where examples of traditional healing method can be harmful, many medicines used today were previously used in traditional medicine. The main ingredients in key glaucoma medications, for example, come from natural sources: taxol from yew bark, and pilocarpine from jaborandi (*Pilocarpus microphyllus*) (Zelefsky and Ritch 2010:657). Thus, "in the absence of clinical trials it devolves upon us to make the best possible guess as to what might or might not be effective in glaucoma" (Zelefsky and Ritch 2010:657). Also, Ghanaian patients tend to seek care from both western and traditional providers "using whichever method is most accessible or promises the best likelihood of healing in that situation" (Klip 2010:5). However, sometimes using traditional healers can "cause a delay in patients seeking and receiving the correct medical treatment," leading to "frustration for the health worker, grief for the family, and irreversible blindness for the patient" (Abdull 2012:44). Thus, a solution to the conflict between traditional and western medicine should be sought, as this creates a socio-cultural barrier to glaucoma care.

Note about Barriers

The aforementioned literature review of barriers to care at the levels of misunderstanding prevalence, missing diagnosis, and poor treatment intersect with psychological, economic, structural, and socio-economic factors. It is important to note that none of these barriers occur without some input from the others. Also, the specific barriers mentioned in this proposal are limited – there are others documented in the literature which have not been fully addressed in this thesis.

Methods

Quantitative Methodology

The research for this thesis was carried out with a mixed methods approach. The quantitative aspect of the research involved the use of a de-identified (name-free and birthdate-free) patient dataset provided by the optometrist running the partner eye clinic outreaches in Kumasi from July 2013, which included information on outreach location, age, gender, symptoms, VAR/VAL (visual acuity), diagnosis, and treatment for 969 patients in Ghana. According to guidelines provided by Lehigh IRB, IRB approval for the quantitative data was not required because there was no identifying information and the data was collected before the proposed research project was initiated. The data came from 14 rural outreaches around Kumasi, Ghana, with approximately 69 patients per outreach (with a wide range of 21 to 142 per outreach, depending on patient recruitment). The data was thus not a random sample, but was rather dependent on the patients that showed up to the outreach; it will thus be referred to as the patient population. The patient population was self-selecting and potentially highly biased. Thus, prevalence in the patient population is not to indicate prevalence in Ghana in general, or even at other outreaches or other times of the year. These limitations must always be kept in mind, as the analysis was carried out with the highly imperfect data that was collected before the research was initiated.

The data was cleaned, fixing a variety of human data input errors, as well as some inconsistencies in symptom description, diagnosis, and specificity of VAR/VAL. Human error could never be fully ameliorated, if volunteers entered data incorrectly in a way that

cleaning could not fix. It was not possible to ensure that all inconsistencies were removed. The maximally-cleaned data was then loaded into and analyzed using STATA 12. The patient population was first described according to age distribution, distribution of patients across villages/locations, sex distribution, combined age/sex distribution, and visual acuity of the patient population (See Tables 1-4).The patient population was also described according to the prevalence of the various diagnoses (See Table 5). Glaucoma was next focused on specifically, looking at glaucoma prevalence according to various age categories using chi-square analysis as well as the mean age of glaucoma patients versus non-glaucoma patients using t-test (See Table 6). The likelihood of having glaucoma by age was likewise looked at using logistic regression. Glaucoma was additionally described according to village/outreach location (See Table 7), and the age distribution of each village was compared to the glaucoma prevalence (See Table 8). Lastly, glaucoma prevalence at each visual acuity level was analyzed (See Table 9). An initial foray into mapping the villages/outreach locations showed that half of the villages could not be identified on a map, while the other half showed no pattern in glaucoma distribution geographically. As such, GIS mapping was not pursued as originally planned. Note that data only on Ghana, in the Kumasi area, was used in the quantitative analysis; data on the Chennai, India outreaches was not available and not used.

Qualitative Methodology

The qualitative aspect of the thesis involved the use of data gathered in Ghana and India. The Ghanaian data was obtained during researcher participant observation at Unite For Sight daily outreaches run by three clinics – one in Kumasi and two in Accra, Ghana

– from July 20th to August 20th, 2013. The Indian data was obtained during researcher participant observation at a clinic in Chennai, India during outreaches from January 7th to January 15th, 2014. The data consisted of forty daily blog entries (thirty three from Ghana, seven from India), each approximately one single-spaced page in length. The entries were based on observational experiences during twenty-two outreaches to twenty-two different locations as well as information learned from conversations with clinic employees, other volunteers, and community members (all of whom remain anonymous in the research) in Ghana and India. The use of the blog entries from Ghana and India as a source of data was approved by Lehigh University IRB on November 7th, 2013 and December 11th, 2013, respectively. The approval timeline is unusual because the Ghanaian blogs were written prior to the initiation of the research project, whereas the Indian blogs were written after the project was initiated, in order to add a comparative perspective to the research.

Three levels of barriers were conceptualized as preventing successful glaucoma care: barriers to understanding prevalence, barriers to diagnosis, and barriers to treatment. Each piece of information fits under at least one of these levels and each was additionally coded as structural, economic, psychological, and/or socio-cultural. Additionally, each barrier was coded as either program-level or patient-level and was specific to either Ghana or India. Grounded theory was used to allow these codes to emerge, while also relating the themes to existing literature. Microsoft Word software was used instead of the initially planned ATLAS.ti, because ATLAS.ti software was unavailable on my Apple computer. Thus, codes were applied using comment boxes in Word, and pertinent

data was then extracted from the Word documents, organizing the data according to themes in new theme-specific Word documents. The write-ups followed from the data in each theme-specific Word document.

In the end, the structural and economic themes were merged into one, as it was difficult to discern if a barrier was structural or if it was actually caused by an economic issue. Similarly, the themes of psychological and socio-cultural barriers were merged into one, because it was difficult to know whether a barrier to care was psychological or socio-cultural in nature (particularly from a vantage point of a foreigner doing research in Ghana and India). Intersecting with these structural/economic and psychological/socio-cultural themes, the barriers were identified as pertaining more to the program or more to the patient. Thus, for each of the three levels of care (understanding prevalence, diagnosis, and treatment), the qualitative results are organized as follows: structural/economic barriers (program-side or patient-side) and psychological/socio-economic barriers (program-side or patient-side) (see Fig. 3 for a visual summary). Some sections are indeed split into two (i.e. separate section for structural and economic) because of a large amount of data that could be separated out; some sub-sections are missing because no data was observed for that section. Intersecting with the structural/economic and psychological/socio-cultural at the program-level or patient-level, the barriers are also compared in terms of location – Ghana and India – as some barriers are being ameliorated in one location, and not in another. As such, reduction in barriers is another code used throughout the results to illustrate the different progress towards reducing barriers to glaucoma care.

Results

The results of this thesis are presented in two sections – quantitative and qualitative. The quantitative analysis is summarized in Tables 1-9, whereas the qualitative framework and results are seen in Figures 3 and 4. The quantitative analysis does the work of better understanding glaucoma prevalence at Unite For Sight partner clinic outreaches around Kumasi, Ghana. The qualitative analysis is broader, reporting on the barriers of misunderstanding prevalence, barriers against obtaining a glaucoma diagnosis, and barriers to glaucoma treatment at Unite For Sight partner clinic outreaches in both Ghana and India. Thus, while the quantitative part of the research informs glaucoma prevalence in the patient population, overall the quantitative and qualitative sections achieve slightly different aims – one elucidating the prevalence of glaucoma, and the other elucidating the barriers to glaucoma care. Both are important and complement each other.

Quantitative Data Analysis

Description of the Data

The quantitative data consists of a cross-sectional dataset of patients attending Unite For Sight partner clinic outreaches around Kumasi, Ghana during July 2013. The data set consists of 969 individual patients. The age, sex, village/location of the outreach, visual acuity of the right and left eye (VAR and VAL), and diagnosis is recorded for each patient. The data was gathered from 14 locations, most of them rural villages, with a mean number of 69.21 patients at each location and a range of 21 to 142 patients (outreaches around Kumasi tended to be smaller than the ones around Accra). There are

14 possible diagnoses, and some patients have up to four conditions diagnosed (for example, allergies in addition to glaucoma). While this research will look at the dependent variable of diagnosis of glaucoma (glaucoma being present or absent), other diagnoses available in the data include presence of suspicious disc, traumatic glaucoma, pterygium, allergies, cataract, immature cataract, phakia, presbyopia, refractive error, macular degeneration, macular scarring, age-related macular degeneration (ARMD), and corneal scarring.

Demographics of the Patient Population

The mean age for the patients is 47.79 years, with a standard deviation of 21.83 years and a range from 1 year to 100 years. I first broke down the age data is into three age categories (25 years and younger, 26 to 49 years, and 50 years and above). The results are visible in Table 1, with 50.05% of the patient population in the 50 and older age category. The reason for this initial breakdown is because the optometrist in Kumasi recommended that those 25 and under with glaucoma get an eye check every year, those 26 to 49 with glaucoma get an eye check every 6 months, and those 50 and above with glaucoma get an eye check every 3 months.

Another way I looked at age is by much narrower categories, similar to the way age has been broken down in other glaucoma prevalence studies in Ghana (Ntim-Amponsah et al 2004b) (Budenz et al 2013). Both Ntim-Amponsah and Budenz only looked at glaucoma in those over 30 years old, either by decade or by 5-year increments. One way I chose to look at age is in eight 10-year increments, as per the Budenz et al 2013 study; the 5-year increments in Ntim-Amponsah et al 2004b were too narrow and

not enough cases were present in each category. With the 10-year increments, I chose to divide the patient population into 8 categories of those 20 and younger, 20-29, 30-39, 40-49, 50-59, 60-69, and 70-79, and 80 years and above. This allowed for some balance of cases within each category. The results of dividing the patient population into 8 categories are visible in Table 2. Note that there are a total of 942 patients with data for age, although the dataset contains 969 patient names.

The sex distribution of the patient population is 43.14% male and 56.86% female. This sex distribution varies statistically significantly by the three age categories (Chi square=9.44, p=0.009). The sex distribution varies insignificantly by the eight age categories, but it varies weakly significantly when reducing the number of categories to six (to see if significance can be found if slicing the age categories differently), with 29 and under, 30-39, 40-49, 50-59, 60-69, and 70 and above being the six categories (Chi square=10.74, p=0.057). The total sex distribution and distribution by the significant age categories is visible in Table 3.

Measuring Visual Acuity

Visual acuity is measured for the right eye (VAR) and the left eye (VAL) and is labeled from 6/6 (normal vision) to 6/9, 6/12, 6/18, 6/24, 6/30, 6/36, and 6/60 (decreasing vision). A VAR or VAL of 6/6 means that the given eye can see at 6 meters what an eye with normal vision can see at 6 meters. A VAR or VAL of 6/60 means that the eye can see at 6 meters what an eye with normal vision can see at 60 meters. Someone with 6/60 vision is considered legally blind in the United States, although level of impairment is not absolute, but is relative to the life demands and impact on life quality for the individual

(Trinity University 2014). For patients who cannot see at 6/60, visual acuity is recorded as CF5M, CF4M, CF3M, CF2M, and CF1M. Such patients can count fingers at 5 meters, 4 meters, 3 meters, 2 meters, or 1 meter, respectively. For patients who cannot count fingers at 1 meter, HM (perceiving hand motions), PL (perceiving light), or NPL (not perceiving light) is used. Because young children are unable to read an eye chart, their visual acuity is not recorded. See Figure 1 for an approximation of vision with different acuities.

Visual Acuity of the Patient Population

For the right eye (VAR), 42.41% of patients have 6/6 (normal) vision. 80.80% have a VAR of 6/36 or better, while 15.07% have a VAR of 6/60 or worse and are considered legally blind in the US. The remaining 4.12% are children (who are unable to read a visual acuity chart). It is important to note that comparing visual acuity between eyes (i.e. VAR versus VAL for a given patient) is beyond the scope of this thesis; however, patterns of visual acuity for the left eye are similar to patterns for the right eye. The visual acuity of the patient population is shown in Table 4.

Prevalence of Glaucoma

Glaucoma and Other Diagnoses

Glaucoma was diagnosed in 28.17% of the patients, with only allergies being more prevalent at 48.61%. Presbyopia comes in third (27.45%) and cataract comes in fourth (11.25%). Some patients have multiple conditions, and this is why these figures add up to over 100%. The distribution by diagnosis is shown in Table 5.

Demographics of Glaucoma

Patients who have glaucoma are 51.10 years old on average, with a wide standard deviation of 20.03 years. Patients who do not have glaucoma are 46.50 years old on average, with a standard deviation of 22.38 years. Using a t-test shows that the differences in age between those with and without glaucoma are statistically significant (t=-2.96, p=0.0016). Looking at glaucoma by three categories of age using chi-square analysis shows the differences by category to be weakly significant (Chi square=5.43, p=0.066). Looking at glaucoma by eight categories of age (19 and under, 20-29, 30-39, 40-49, 50-59, 60-69, and 70 and above) is likewise weakly significant (Chi square=13.22, p=0.067). The significant results are visible in Table 6.

The prevalence of glaucoma does not differ statistically significantly by sex (Chi square= 0.065, p=0.799). When looking at glaucoma's relationship to sex for each of three age groups, the results are not statistically significant either. However, when looking at glaucoma's relationship to sex for each of the eight age groups, there is a significant difference in glaucoma prevalence only between males and females for the 40-49 age group (Chi square=4.29, p=0.038). In this age group, 22.89% of males but 37.36% of females have glaucoma. It is only in this age group that the prevalence of glaucoma differs significantly by sex, something future research should look into.

We can also examine how variables such as age and sex influence the likelihood of having glaucoma using logistic regression. Linear regression is not used because this requires a continuous dependent variable, whereas having glaucoma (or not) is a categorical/dummy variable. Using logistic regression, each additional year of life

increases the chance of glaucoma by 0.99%, and this is highly significant at p=0.003. When looking at age according to the three age categories, an increase in age from the under 25 to the 25-50 age category increases the likelihood of glaucoma by 50.47%, although this is not highly significant (p=0.066). Moving from the under 25 to the 50 and older category increases the likelihood of glaucoma by 61.38%, and this is strongly significant at p=0.021. These results hold when controlling and not controlling for sex, which is not significant for the probability of having the glaucoma outcome.

Similarly, looking at the likelihood of having glaucoma by eight age categories, all of the categories are significant. Moving from the 19 and under category to the 20-29 category increases the chance of glaucoma by 137.96% (p=0.010). Moving from the 19 and under age category to the 40-49 age category increases the chance of glaucoma by 136.52% (p=0.027). Moving from the 19 and under age category to the 70-79 age category increases the chance of glaucoma by 139.99% (p=0.005), and it is only for the 80 and over category that moving from 19 and under to 80 and over increases the chance of glaucoma by 219.99% (p=0.004). Thus, the chance of glaucoma jumps when transitioning from the under 19 category to the 20-29 category, and stays roughly the same until the 80 and over category. Thus, the change in the chance of getting glaucoma relative to age is not linear, but increases quickly early in life and then later in life.

The prevalence of glaucoma differs significantly among the 14 village sites (Chi-square=30.61, p=0.004) (Table 7). The prevalence of glaucoma ranges from a low of 15.05% in Kwanwoma to a high of 38.71% in Asamang. When looking at such villages that have a very high and relatively low prevalence, this may be partly explained by the

age distribution of the patients attending the village outreach. In Kwanwoma, which has the lowest prevalence of glaucoma at 15.05%, 44.09% of the patients are 50 and older. In Asamang, 70.97% of the patients are 50 and older, and the prevalence of glaucoma is 38.71%. The breakdown of each village/outreach by each of the 6 age groups is shown in Table 8. However, none of the relationships between glaucoma diagnosis and age group (when age is divided into three groups) are statistically significant, when bysorting by village. When bysorting by three age groups, there is a statistically significant difference in the relationships between prevalence of glaucoma by village/location only for the 25-50 age group ($p=0.016$); glaucoma diagnosis by village via the other two age groups are not statistically significant. When sorting by six age groups (as eight age groups show no significance anywhere), there is a statistically significant difference in the relationship between prevalence of glaucoma by village/location only for the 40-49 age group, but there are not enough cases in many of the villages for this age group to make the result reliable (Chi square=24.79, $p=0.025$)

When looking at the relationship between prevalence of glaucoma and village/location by sex, there is no statistically significant difference for either males or females.

The prevalence of glaucoma does differ statistically significantly by visual acuity level, by both VAR (Chi square=48.25, $p=0.000$) and VAL (Chi square=36.15, $p=0.010$). The prevalence of glaucoma at each level of VAR and VAL is shown in Table 9. Looking at the distribution of glaucoma across different visual acuity levels, 23.60% of patients with a VAR of 6/6 have glaucoma, and this increases to 44.44% for patients

perceiving hand motions and 45.45% for patients not perceiving light. A similar trajectory is seen for the left eye, with 26.42% of patients with glaucoma having 6/6 VAL.

Quantitative Discussion

Several interesting insights can be gathered from the data which have implications for how glaucoma can be addressed, particularly in Ghana. Most obvious is the fact that glaucoma is very common at Unite For Sight partner clinic outreaches in Kumasi, Ghana, in that 28.17% of patients in July 2013 were diagnosed with glaucoma. Of course, this cannot be extrapolated to represent the prevalence within the Ghanaian population, since the patients attending the clinic are not a random sample and are self-selecting in that they choose to come to an outreach perhaps because of a known eye condition or even a pre-existing glaucoma diagnosis. However, this statistic is important for how outreaches may be structured to better address the needs of patients who are diagnosed with glaucoma at Unite For Sight partner clinic outreaches in the future. The bias in this patient population also shows the difficulty of understanding prevalence, which makes understanding and thus diagnosing and treating glaucoma difficult. Only random-sample population-wide studies should be used for larger policy decisions regarding glaucoma.

Another very interesting and important observation is that glaucoma is highly prevalent in younger age groups, which is unusual, as glaucoma is thought to afflict mostly older individuals. 21.23% of the 25 and younger age group has glaucoma, and this is emphasized by the existence of a separate diagnosis of a suspicious disc, which is an early sign for glaucoma. This suspicious disc diagnosis, present in 7.26% of the 25 and

younger patients, tempers the likelihood of over-diagnosing glaucoma and suggests that glaucoma is truly present in such young patients. This knowledge should be incorporated into who is targeted by the community liaisons for outreaches, and about how glaucoma is presented in health talks – it is clearly not a disease that impacts only the elderly.

In addition to the young age of glaucoma patients, visual acuity (particularly a normal state of it) is not a good predictor of the likelihood of glaucoma. 23.60% of patients with a visual acuity of 6/6 (normal vision) have glaucoma, although this percentage increases greatly to 45.45% in patients who are NPL (not perceiving light). Still, the 23.60% figure illustrates the asymptomatic nature of glaucoma progression, as central vision remains normal until the late stages of disease (see Figure 2). Thus, a simple visual acuity test alone, without an optic nerve exam or perimetry (testing peripheral vision) can miss glaucoma diagnosis. Thus, a comprehensive exam should be emphasized, and patients should never be told that perfect vision means perfect eye health.

The fourth finding of the data is that glaucoma prevalence varies highly significantly from village to village, from 15.05% to 38.71%. However, this can potentially be explained by different age distributions at different outreaches. Preliminary mapping of the outreaches showed no geographic pattern in glaucoma prevalence by location. Thus, further research into locality-specific differences of glaucoma prevalence should be carried out.

The last finding is that sex does not seem to matter for the glaucoma diagnosis – it is equally prevalent in both sexes, even when controlling for age. This finding is quite

interesting and shows that, unlike many conditions, both males and females, of all ages, and of all visual acuity levels should be equally targeted by outreach efforts.

Limitations

This dataset is highly limited in that it is cross-sectional, only encountering a patient at a given moment in time without additional data from previous or past encounters with eye care professionals. This limits the ability to understand the progression of glaucoma in patients. The data was gathered from July 2013, and it is thus limited temporally to patients who attended outreaches at that time. It is unknown if data from other months would have yielded different results. It is not a random sample, but rather a self-selecting patient population. Additionally, the data is obtained from work done by one eye care professional working in a geographically limited area. The optometrist was also highly passionate about glaucoma and may have been over-diagnosing glaucoma, and the impact of this is unknown. Concerns about potential over-diagnosis are, however, somewhat controlled by the possibility of suspicious disc diagnosis and variation in glaucoma prevalence from village to village.

All of these limitations in the data curtail our ability to extrapolate to other regions of Ghana, not to mention other parts of West Africa. Another limitation is the inability to know whether patients attending a certain outreach actually originate from that village, or if they traveled there for the outreach. This limitation introduces bias into any connections being made between location and glaucoma prevalence.

Another limitation of the data is that only a few variables are available for analysis. For the purpose of studying glaucoma, it would be useful to know if there is a

family history of glaucoma and if the patient has ever had an eye checkup. Other more general demographic factors of interest would be the education level, occupation, and income, as these may relate to access to eye care and thus to progression of glaucoma. Data on the components of the glaucoma diagnosis (for example, intraocular pressure measurements, visual field test scores, and optic disc to cup ratio measurements) would have greatly enhanced the analysis by allowing for an ability to study the conclusiveness of the glaucoma diagnosis.

Qualitative Data Analysis

Barriers to Understanding Prevalence

I define barriers to understanding prevalence as the process before any outreaches occur – in the more general understanding of the problem of glaucoma. A misunderstanding of prevalence precedes the lack of diagnosis and treatment of glaucoma. In short, both programs and patients are unaware of how prevalent glaucoma is. Barriers to understanding prevalence are mostly program-side, although patients contribute to misunderstanding prevalence by not attending health talks and by general lack of health/eye care education in patients.

Program-side, there is a lack of research on glaucoma by Unite For Sight, which has a Global Impact Lab that assigns interested volunteers a research project. Additionally, the decision-making power over research questions, which are obtained from the partner clinics – of the players who are most in contact with glaucoma patients and those who make decisions on research studies – make glaucoma a less emphasized

disease compared to cataract. Additionally, the structure of the outreaches makes research difficult, since poor (or no) recordkeeping makes data analysis problematic.

Understanding Prevalence: Program-Side Barriers in Ghana and India

Structural/Economic

One big program-side problem is the lack of substantial studies on glaucoma by Unite For Sight volunteers, who can participate in a research study during their volunteering via the UFS Global Impact Lab. Out of 86 research studies listed on Unite For Sight's Global Impact Lab's page of past research studies, only 7 address glaucoma directly (UFS 2013c). In the Global Impact Lab, volunteers (often students who have a research background) are given a research assignment – a research question that has been asked to be studied by the partner clinic. I was initially a researcher evaluating the eye care knowledge of informal volunteers – community members who help out during outreaches without any formal affiliation with UFS or the local partner clinic. Upon arrival in Ghana, my research question was met with quizzical looks by other volunteers as well as local Ghanaian clinic staff:

> [The optometrist] was surprised by the topic – apparently she hasn't seen many informal volunteers on outreaches. One of the other volunteers commented that he has seen patients volunteer, for the sake of making the outreaches go faster. So, as of right now, I am worried about my research project – what if there aren't any informal volunteers to interview? (Ghana Blog, July 21st, 2013)

In other conversations with volunteers, I heard of others doing similar research projects that they felt to be disconnected from the reality in Ghana. While I did as much of such a research project as I could, I found glaucoma to be a real pressing issue. However, it does not seem that glaucoma is an issue being studied deeply by the UFS Global Impact Lab (as mentioned previously, seven studies have been done on glaucoma by UFS volunteers in the past). This contributes to the barriers to understanding glaucoma prevalence.

Once a study of glaucoma prevalence is attempted, I can foresee one major barrier to doing such research, related to the program structure. Outreaches in Chennai have absolutely no recordkeeping. Certain Ghanaian outreaches keep sporadic records, and only one outreach (out of dozens) keeps information on each patient longitudinally, from outreach to outreach. This makes studying prevalence and other aspects of glaucoma (such as treatment outcomes) extremely difficult (although this research could better be considered incidence research, as it is the number of glaucoma cases per group of patients who come to the outreaches). While research via UFS outreaches certainly may not be random and does not represent the population of Ghana, it is still helpful for understanding the needs of the patients who attend UFS partner clinic outreaches. The poor or lack of recordkeeping at outreaches makes it difficult to understand such prevalence/incidence and glaucoma treatment outcomes.

As mentioned in the literature review, there is also a lack of population-wide research studies on glaucoma prevalence (one such study specific to Ghana, still deemed "incomplete", and five such studies in India). Such population-wide studies are the

responsibility of larger institutions of learning and international organizations and governments; thus, a concerted approach both by organizations such as UFS and by larger organizations and governments is needed to better understand glaucoma incidence and prevalence in both India and Ghana.

Psychological/Socio-cultural

Looking at the types of studies done via the UFS Global Impact Lab perhaps suggests that partner clinics are not requesting research studies about glaucoma prevalence. This may occur for many reasons. One reason is that the local clinics are unaware of glaucoma and how prevalent it is, or may see such prevalence as normal and expected and not something to question or study. Another explanation is that there is a mismatch in who assigns/suggests research questions and who is in closest contact to the patients. It seemed to me that it was the ophthalmologist at each clinic who decided on the research study topics. However, it is the optometrists who go to the outreaches daily, as the ophthalmologists (in both Ghana and India) stay in the clinic. Lack of communication or a distant relationship between optometrists and ophthalmologists may be leading to a lack of research on glaucoma prevalence. This may be reinforced by a partner organization such as Unite For Sight subsidizing and, thus, emphasizing cataracts or other conditions over glaucoma.

However, one Ghanaian clinic worker was indeed very interested in understanding glaucoma prevalence, and spoke to me about doing an analysis of glaucoma prevalence from the patient data that is available:

> [S/he] is seeing an increasing number of young people with glaucoma, which worries [him/her]. [S/he] wants to understand why it is so prevalent among people of some villages but not others – [s/he] believes that it is due to genetic factors, where there is a lot of intermarriage within certain villages. (Ghana Blog, July 26th, 2013)

Such individuals help reduce the barriers to understanding glaucoma prevalence, and certainly need larger institutional support via further research.

Understanding Prevalence: Patient-Side Barriers in Ghana and India

Psychological/Socio-cultural

Patients being late to the outreach and missing a health talk means that they do not learn about glaucoma and its prevalence in the population. Only Ghanaian outreaches do such health talks, so patients in Chennai do not have access to understanding about glaucoma prevalence because of a lack of a health talk. It is beyond the scope of this thesis to determine whether patients obtain education about glaucoma from other sources; certainly lack of education – whether from UFS or from other sources – contributes to patient-side barriers to understanding prevalence.

Barriers to Diagnosis

In this section, I report on the barriers to glaucoma diagnosis. I define diagnosis broadly – from getting the patient to attend the outreach to the patient going through the outreach screening process all the way until contact with the optometrist or other clinician occurs, leading to the diagnosis. Barriers to diagnosis occur at both the program-

side level as well as the patient-side level. Program-side barriers include the geographic distribution of outreaches; lack of access to other eye health care facilities unaffiliated with UFS-partner clinics; requiring patients to pay a fee to participate in the outreach (used to pay for the community liaison's advertising for the outreach); referrals to an ophthalmologist rather than diagnosing the patient at the outreach; different clinic staff emphasizing and being aware of glaucoma to a different extent. Patient-side barriers include time and cost of traveling to and time spent at the outreach (and opportunity costs associated with each); financial payments at the outreach; the locations of outreaches at churches; other social obligations that take priority over eye care; misunderstanding the role of glasses versus comprehensive screening and eye medication; difficulty of accepting an asymptomatic and early-onset diagnosis; language barriers between staff/volunteers and patients. Reductions of barriers to diagnosis include community liaisons who advertise about the outreach and help in patient registration and in-take; targeting multiple, different villages during each outreach to a location; comprehensive eye checks (rather than only screening for cataracts); health talks that inform and make acceptance of a diagnosis potentially easier.

There are large differences in the barriers to diagnosis of glaucoma in Ghana versus India. The programs are very different in their level of addressing barriers to glaucoma care. As such, some actions that are taken in Ghana can be considered a reduction in barriers to glaucoma diagnosis, but the same barrier-reducing actions may not be taken in Chennai, India. This difference from country to country serves to reinforce the importance of being specific about the analysis of barriers to glaucoma care

– different programs have different barriers and are addressing the barriers differently. No single solution can be used for all locations.

Diagnosis: Program-Side Barriers in Ghana and India

Structural/Economic

One barrier to diagnosis is that the location of outreaches is determined by the outreach clinic having a connection to someone in the community. Thus, communities that may have high rates of glaucoma may not be visited by the outreach clinic at all, because of lack of a community liaison. Perhaps the next steps in reducing this barrier to diagnosis would be to ensure that outreaches are geographically well-distributed and reach all communities. However, it is unknown if other organizations may be functioning in other areas, so perhaps this barrier maybe overstated. Regardless, this is too large of a feat for a non-profit organization or clinic and is instead something the Ghanaian government or larger entities should be responsible for. In India, the outreaches were additionally solely concentrated in urban areas around Chennai, thereby eliminating the possibility of diagnosis via UFS partner clinics for patients living in rural areas, who are more likely to be poor and have low access to eye care.

Other barriers to diagnosis occur in the lack of access to other healthcare facilities that can provide a diagnosis, other than the outreach. For example, one clinic still holds outreaches to an area that actually has an eye clinic because, as a Ghanaian optometrist explained, "a consult at the relatively nearby clinic is 15 cedi and the eye drops are twice as expensive as at our outreach" (Ghana Blog, July 23rd, 2013). Thus, the lack of affordability within the local healthcare infrastructure is a barrier to diagnosis of

glaucoma (and also a barrier to treatment, as patients require regular check-ups for their glaucoma). In Chennai, I was surprised that outreaches were held in urban areas given the high concentration of eye clinics, but, similarly, this was because the outreaches served people who otherwise cannot afford to get screened at local facilities.

There was one potential reduction in the barrier to diagnosis in that some clinics provided a stipend to the local community liaison/worker for recruiting patients. Some clinics collected 1 cedi from the patients attending an outreach and this provided the stipend for the liaison with the following effects:

> The community worker took 1 cedi from each patient (this was his payment, and also compensation for any money he spends on publicity). He spends two weeks publicizing daily (3 cedi for a daily community announcement, for example), so he really loses when patients don't show up. (Ghana Blog, July 31st, 2013)

As such, the liaison has an incentive to maximize the patient turnout at the outreach, thereby allowing for a reduction in barriers to glaucoma diagnosis. Other clinics provided a payment for each patient referred for cataract surgery (rather than per patient attending the outreach), so liaisons in such community obtained less remuneration for their advertising. In either situation, the community liaisons had an incentive to attract as many people to the outreach as possible. However, any fee to participate in the outreach could have also deterred patients from going through with the screening, even if they decided to come to the outreach. Additionally, not all outreaches provided a payment to the liaisons (regardless of how many patients showed up, as policies seemed to differ by location);

several outreaches would have turnouts as low as 40 patients, because the community liaison would not do a good job at recruiting. Thus, the economic incentives given or not given to community liaisons had differing effects on barriers to glaucoma diagnosis.

Another aspect of the program can be seen as both a reduction of barrier to diagnosis but also an increased barrier to treatment. One nurse in Ghana explained that a different set of neighboring villages is targeted during repeated outreaches to the same location. More people have a chance to get diagnosed when multiple different villages are targeted, but this provides a barrier to treatment for returning glaucoma patients, who have to keep track of changing community liaisons and the varying modes of advertisement about the outreaches. The clinic driver in Chennai similarly explained that the outreaches in India constantly target a different area or urban location. This increases the likelihood of diagnosis by allowing for a basic eye check and referral to an ophthalmologist, but also presents a challenge to treatment (although outreaches in India do not diagnose or treat glaucoma in the first place because of optometrists' practice limitations).

Another reduction of barriers to diagnosis was seen with the help of the liaison and other members of the community during the outreach. At many outreaches, upon the clinic's arrival, the community liaison and various assistants or community members would already be doing registration and visual acuity. This reduced the waiting time during the outreaches (which usually was very long and took several hours at the least), thereby increasing the chance that a patient would wait their turn to see the optometrist and get the diagnosis. However, the very size of some of the outreaches (in the hundreds

of patients) meant that people may have left the outreach before getting diagnosed, although I did not observe this happening – patients seemed to wait their turn. Still, the size of the outreaches can be seen as a barrier to diagnosis (and treatment, for those returning for a checkup).

The comprehensiveness of outreaches in Ghana also reduced the barrier to glaucoma diagnosis. All patients in Ghana had their optic nerve observed to check for glaucoma. However, this was not the case in Chennai, as the outreaches only checked for cataract, refractive error, or presbyopia and did not check the optic nerve. This is partly related to the fact that optometrists in India are not legally permitted or qualified to diagnose advanced eye conditions such as glaucoma, and must refer such cases to an ophthalmologist. Optometrists in Ghana, on the other hand, all used a direct ophthalmoscope to check for glaucoma, whereas such equipment was not present at the outreaches in India. Instead, advanced cases in India would be identified with the pinhole test, which uses a particular set of lenses to correct vision problems caused by errors in focusing. All other conditions not caused by errors in focusing (such as diabetic retinopathy, glaucoma, age-related macular degeneration, etc.) would not be corrected by the pinhole test, and this would be the red flag for the optometrist to refer the patient to an ophthalmologist. However, in India, "patients who were 6/6 or 6/9 were told that they were normal without further examination [i.e. without the pinhole test] and were told they could leave, unless they had another complaint that was bothering them that they wanted to address" (India Blog, January 9th, 2014). Thus, patients who presented with normal vision in Chennai often did not undergo the pinhole test and thus early stages of

glaucoma (when it is asymptomatic and vision is still perfect) do not get diagnosed in India. In Ghana, patients with 6/6 vision still underwent the entire clinic process and had their optic nerve checked for glaucoma.

In India, for those who do obtain a pinhole test and still have problems seeing and are suspected to have something other than cataracts, the optometrist refers the patient to a nearby ophthalmologist. As the ophthalmologist in Chennai told me, nearby ophthalmology practices are referred to in order to not offend local doctors. However, it is unknown how many patients follow through with such referrals, highly problematic for asymptomatic glaucoma cases:

> I was really frustrated throughout the outreach about how non-comprehensive the camp[i.e. outreach] is. It basically only looks for cataracts. This means that many patients walk away thinking that they are completely fine when, in fact, they might have an asymptomatic condition and are not getting properly checked. I am not sure if I buy the whole idea that they should just instead go to their local hospital – they won't if they don't have the money, and now they have had false reassurance that there is nothing to worry about. I know glaucoma isn't highly prevalent [in India], but still, in an outreach to 50 people, if 1 person has glaucoma, that is 1 potentially and irreversibly blind person. That is a tragedy. (India Blog, January 9th, 2014)

Psychological/Socio-Cultural

Daily observations of the various clinic staff in Ghana suggested conflict among staff which might reduce the effectiveness of the program. Different members of staff occasionally had differing views on what is important for the program to address, and this manifested in different clinics emphasizing glaucoma to a different extent. Some optometrists had a strong emphasis on glaucoma, while other staff members did not did not feel so passionate about this particular condition. However, some optometrists may have also been over-diagnosing glaucoma, possibly because the interpretation of nerve damage can be somewhat subjective as optic nerve structures differ from person to person. Conversely, optometrists who are not particularly looking for glaucoma may under-diagnose it. Also, there was usually one optometrist at each outreach who made the final diagnosis, and a second opinion was not available. However, one clinic in Ghana did have two optometrists/ophthalmic nurses at their outreaches and they occasionally collaborated on an unclear case. Additionally, some clinics emphasized glaucoma screening as part of a larger comprehensive screening process because, as one optometrist explained, not providing comprehensive treatment lowers the credibility of the outreaches and the clinic. The complex motivations for providing diagnosis are outlined in this entry:

> [The optometrist] explained that simply giving [a patient] reading glasses would have 1) not stopped her glaucoma from progressing and 2) would have tarnished [the clinic]'s and [the optometrist]'s reputation as being irresponsible and of not fully diagnosing the woman. Thus, it is important

> for all patients to go through a full screening before they get any medication or glasses. (Ghana Blog, July 29th, 2013)

Thus, possible challenges to a clinic's or optometrists' reputation in Ghana certainly encouraged comprehensive care, including checking for glaucoma. Observations on this issue were not made in India.

Diagnosis: Patient-Side Barriers in Ghana and India

Structural/Economic

One very common barrier to diagnosis for virtually any health problem is the distance patients have to travel for treatment; patients in Ghana came from various villages of different distances, although I was not able to assess how far away such villages are. Such travel poses financial burdens on the patient, as well as opportunity costs of taking the time out of their day to travel that they could instead be used for economic or other important activity. Even without travel, patients often spent the majority of a day at the outreach, which perhaps deterred future visits to the outreaches by the patients, and discouraged new patients from attending, given that the length of time spent waiting would certainly become known in the community. Sometimes, the influx of patients traveling from different areas was unexpected, as seen in this entry:

> Apparently, about 200 of the patients today were refugees from Cote d'Ivoire, as there is a refugee camp about ten minutes away from the site where we did the outreach. [The optometrist] explained that there was post-election violence in Cote d'Ivoire two years ago, and some people were displaced to Ghana. (Ghana Blog, August 14th, 2013)

Such days with large numbers of patients posed other key barriers to diagnosis: the optometrist had a limited amount of time to spend with each patient and was possibly more likely to misdiagnose due to increasing fatigue. This was made more complicated if there were language barriers between patients and providers.

Another barrier to diagnosis was when outreaches had registration fees used to cover advertising costs and to serve as financial incentive for the community liaisons. I observed such fees discouraging several (often young) patients who did not have an income and were often asymptomatic from getting a check-up, and this was likely a barrier to glaucoma diagnosis. Several such young patients simply left the outreach without getting screened, because they realized there was a cost to get a check-up.

Psychological/Socio-Cultural

In addition to the economic or structural barriers to obtaining a glaucoma diagnosis, a variety of psychological or socio-cultural factors were potential barriers. One example is that Ghanaian outreaches were nearly always held in Christian churches. While there were many Muslims and Christians present at each outreach, the carrying out of outreaches in churches may have made certain members of the community uncomfortable and may have prevented outreach attendance (although I did not observe this directly). One optometrist explained to me that outreaches could not be carried out in mosques because the Christians would not attend; Muslims came to Christian churches for outreaches, however. In India, the outreaches were typically held in schools and community gathering places, and did not have this potential barrier.

Another barrier to diagnosis was the opportunity costs related to attending social functions or community events versus going to the outreach. Repeatedly seen in Ghana, large groups of patients were late to the outreach by hours because of a funeral in the community. Sometimes, various local conditions such as these meant that an outreach was cancelled or that very few patients attended the outreach. This infuriated one optometrist very regularly, because she disagreed with the prioritization of such socially important events over eye health.

Another highly prevalent barrier to diagnosis of glaucoma is the belief that glasses will cure everything. In short, patients in both Ghana and India did not see the importance of a comprehensive eye check. Even important members of the community who serve as role models and are affiliated with the outreaches had such curative notions about glasses:

> A community member who works at the local radio station showed up to get a pair of reading glasses. He had disseminated information about the outreach to the public. [The optometrist] was very upset that [the man] decided to show up at the end of the outreach, and that he simply wanted reading glasses. She explained that patients often get reading glasses when they actually have another underlying condition causing their vision loss. (Ghana Blog, July 29th, 2013)

The optometrist explained that this misunderstanding stems from a lack of education about eye care, and this is something the clinics in Ghana try to counter via the health talks. Additionally, since patients tended to believe they do not have glaucoma if it

is asymptomatic and early-onset, the health talks provided information that would promote acceptance of the asymptomatic and early-onset glaucoma diagnosis.

Another barrier to diagnosis was the constant language barrier between patients and the clinic workers and volunteers. This was highly prevalent in Ghana, where different regions speak different local languages. Similarly, in Chennai, several patients came in speaking only Hindi, whereas the clinic workers only speak Tamil. Such language barriers made every stage of the outreach complicated, from the initial health talks in Ghana, to the screening, to explaining the treatment. This was handled in a variety of ways – from having someone in the community translate, to using various hand gestures to communicate.

Barriers to Treatment

In this section, I report on the barriers to glaucoma treatment. I define treatment as the process that takes place after diagnosis has been obtained. Of course, this barrier to treatment is only applicable to situations where diagnosis is attainable (for example, barriers to treatment are observed in Ghana, but not in India, because glaucoma is not diagnosed at the outreaches). Barriers to treatment typically occur at either a program-side level or at a patient-side level. Program-side level barriers to treatment occur with reduced access to outreaches given the infrequency, location, and advertisement of outreaches; reduced access to medication because of medication pricing at outreaches; lack of longitudinal patient data keeping; the presence of "siloing" in programs; various interpersonal barriers among the clinic employees and volunteers contributing to barriers to treatment of glaucoma. Patient-side barriers to treatment are also discussed, such as

inability to afford medication, distance of travel to the outreach for repeat check-ups, misunderstanding of the purpose of medication versus glasses, attitudes toward asymptomatic conditions, and language barriers between patients and clinic employees and volunteers. Reductions of barriers to treatment are also discussed, particularly with the use of health talks.

It is important to know that the barriers to glaucoma treatment differed widely from country to country – the barriers in Ghana are very different from the barriers in Chennai, India. Thus, the section goes back in forth in comparing the barriers to treatment in Ghana versus Chennai. Additionally, some barriers may be reduced in one location, but are not addressed in other locations. Such comparison serves to highlight the importance of locality-specific treatment and understanding that a single set of solutions certainly will not remove barriers to treatment in all areas. The programs are very different in terms of progress toward eliminating various barriers to treatment.

Treatment: Program-Side Barriers in Ghana and India

Structural/Economic

One barrier to glaucoma treatment in Ghana resulted from the outreach clinics not returning to the same location frequently enough to provide the medication needed. Outreaches in Ghana returned to some villages every 3 months, for example. However, the standard supply of glaucoma medication usually lasts for a month. Patients would have to have the foresight and economic capacity to purchase three months of medication in advance. Also, some patients with advanced glaucoma may require care that is more frequent than once in 3 months. According to the Chennai, India driver, their outreaches

did not return to the same location twice (and did not sell/provide glaucoma medication). Thus, it is foreseeable that infrequently visited locations, not visiting the same location twice, and not selling medication at the outreaches would have no or reduced access to glaucoma treatment. Since non-adherence to a glaucoma treatment regimen is already high in communities with ready access to medication (for example, only about 56% of patients use more than 75% of the expected doses in the US), not having access to the medication in Ghanaian communities is an additional burden that prevents treatment. Proper treatment otherwise "reduces the development or worsening of glaucoma by at least 60%" and "poor adherence results in greater visual loss and a higher risk of blindness" (Mansberger et al 2013).

Another barrier to treatment in Ghana is that the same health workers would not be used for the same location each time. This occurs because a different set of nearby villages is targeted during each outreach, and a different liaison may be needed to reach these new villages. Thus, the demographic targeted each time is somewhat different, which presents barriers to treatment for patients who require a new supply of medication or a glaucoma check-up, as these patients would have to keep track of advertisements set up by different liaisons, who may be targeting other locations.

For patients who did come back to the same clinic for a second time after several months, another barrier to treatment was that longitudinal patient information was not available. Outreaches in Ghana took down patient information for each outreach, but did not track patients over time. Only at one outreach in Ghana – at a refugee camp near Accra where the same community liaison held patients' records in between outreach

visits – were longitudinal records kept for patients. At another outreach, an entirely different scenario unfolded, where returning patients were not entered into the Excel database at all. At the Chennai, India outreaches, no patient information was taken down. Because of these differences and gaps in patient data, patient history could not be available for comprehensive, long-term treatment.

Another barrier to glaucoma treatment occurred with the cost of medication (and medication was only sold at Ghanaian outreaches, not ones in Chennai). One optometrist in Ghana explained to me that the clinic buys the medication wholesale and then sells it at no profit to the patients, or 4 cedi. Sometimes, during unanticipated turnouts of patients, the outreach would run out of a certain type of medication, making treatment impossible. Additionally, medication prices (for the same exact medication) varied from clinic to clinic during the outreaches (4 cedi in one clinic and 8 cedi at another), and I found prices for the same medication to be lower in pharmacies in Accra (5 cedi). Thus, the pricing for medication was unclear. Additionally, I found that ability to provide discounts for patients who could not afford the medicine differed from clinic to clinic. Some optometrists felt comfortable giving a discount for persistent patients, but other optometrists stated that it is up to the ophthalmologist who owns the clinic to give discounts. Thus, there were differences in access to treatment for glaucoma based on which clinic outreach was attended – there were differences in prices, and differences in the ability to obtain discounted medicine. Unite For Sight, in both Ghana and India, does not subsidize glaucoma medication or any other treatment forms for glaucoma (such as glaucoma filtration surgery).

I was not able to determine where profits (if any) from medication sales go. However, I did find out that some of the clinics have Unite For Sight pay for the gas to the outreaches, and UFS pays the salary of some of the optometrists (this differed from clinic to clinic). Other clinics have a less close-knit relationship with Unite For Sight and do not receive a gas subsidy, and their optometrists are instead employed by the partner clinic. It is possible that some of the profits from medication sales are used to pay for such expenditures, which differ from clinic to clinic depending on program structure. Such differing program structures would have a different impact on the treatment of glaucoma.

One highly evident barrier to treatment from the program side occurred with the "siloing" of programs, particularly notable in Chennai. One way to think of "siloing" is in opposition to integration and one where a healthcare system is "one of fragmented specialists who deliver discrete interventions as opposed to coordinated and integrated care" (Porter et al 2008:3). This is problematic because it does not maximize value in healthcare in terms of "patient health outcomes per dollar spent" – it has many redundancies in health expenditure and also has less positive effect on health outcomes than comprehensive care (Porter et al 2008:3). In India, the partner clinic had several separate programs they were conducting – ones for diabetic retinopathy (working with another external organization), cataracts (via Unite For Sight), etc. This "siloing" was not as highly visible in Ghana, where the outreaches were rather comprehensive and diagnosed as well as treated everything from allergies to cataracts. On the part of Unite

For Sight, an emphasis on cataracts (in terms of policy as well as economic subsidy) could likewise be interpreted as a form of "siloing."

One barrier to treatment particular to India was that optometrists are not qualified to diagnose and treat glaucoma; they are only permitted to diagnose refractive error or presbyopia, and make an initial diagnosis of cataracts. Thus, the optometrist used the pinhole test (which focuses light on the fovea and compensates for and corrects any problems caused by farsightedness/nearsightedness) to flag down advanced conditions. Such advanced conditions such as glaucoma, diabetic retinopathy, or macular degeneration could not be conclusively diagnosed with a pinhole test and, thus, patients failing the pinhole test would automatically be referred to an ophthalmologist. This was a barrier to treatment for patients who had to seek an ophthalmologist's consultation before obtaining definitive diagnosis and treatment. However, the outreaches in India also tried to refer patients to local/geographically proximal ophthalmologists – this helped the local ophthalmologists stay in business, maintained the UFS partner clinic relationships within the ophthalmological community in the area, and allowed patients easier access to the ophthalmologist in terms of travel distance. In this way, the UFS partner clinic in Chennai, India only handled the cataract cases that came in from the outreaches, and referred conditions such as glaucoma to the local ophthalmology practices or government hospitals.

There was one aspect of the program in Ghana that may have reduced barriers to treatment – the use of the health talk. While no health talks took place at the Indian clinic

outreaches, virtually each outreach in Ghana began with a health talk. Here is an excerpt from the blog that characterizes a health talk:

> [The optometrist] began by giving a lengthy health talk, where she described many eye conditions, including an emphasis on glaucoma, which she made the crowd pronounce back to her several times as she explained it… Next, [two of the American volunteers] did a demonstration of how to put in eye drops and eye ointment. (Ghana Blog, July 22nd, 2013)

The health talk is coded as a reduction to barriers in treatment because the health talk occurs after the patients have arrived at the outreach and will go through the outreach process. Thus, the health talk educates patients about the diagnosis they may receive, so that they are better positioned to understand the importance and method of treatment, an integral component of the Health Belief Model. Note, however, that this reduction is not universal as the health talks took place in Ghana but not in India.

Psychological/Socio-Cultural

One socio-cultural barrier to treatment of glaucoma was the outreach program's emphasis on symptoms. Upon arrival at the outreaches in Ghana, patients were asked if they had any itching, burning, tearing, etc. This structuring of the outreaches (and of medicine in general) reinforced the idea that eye diseases likely have symptoms associated with them – which is not true for glaucoma. Furthermore, in India, patients who had no symptoms and had 6/6 or 6/9 vision were often told they have normal vision and can go home. This lack of comprehensive check reinforced the assumption of no

symptoms, no disease. This is highly problematic for glaucoma, which is asymptomatic and preserves central vision until the late stages (see Figure 2).

Another difference observed from clinic to clinic was the level of involvement and passion for the cause of eye care. Some optometrists and clinic workers were extraordinarily passionate about treating all conditions, whereas others were very ineffective at educating the patients or about being comprehensive in their checkups. Such individual-level variables influenced patient treatment outcomes.

Lastly, language barriers between clinic employees and foreign volunteers, as well as volunteers and patients, often formed another barrier to treatment. Because volunteers were actively involved in every step of the outreach process, dispensing medications often fell on the volunteers. While there was typically a clinic employee around, misunderstandings between volunteers and patients likely occurred and may have influenced treatment (i.e. misunderstanding about dosage frequency). Similarly, misunderstandings between volunteers and clinic employees may have compromised the quality of treatment.

Treatment: Patient-Side Barriers in Ghana and India

Structural/Economic

One of the most pronounced barriers to glaucoma treatment was the inability of some patients to pay for their glaucoma medication, which ranged from 4 to 8 cedi, depending on the outreach. Patients who were unable to, or sometimes did not understand the importance of, buying the medication were given a piece of paper with the name of the medication along with the dosage (not a formal prescription, just a note that even

volunteers could write). Patients could then go to a pharmacy and pick up the medication, although the distance to a pharmacy posed another barrier to treatment. As mentioned previously, patients would sometimes be given a discount, but this depended on which clinic's outreach they happened to attend. Some patients did try to "game the system" by appealing to the volunteers for help to pay for the medication; once, when a clinic employee denied a discount, the patient was seen taking out a large wad of money to pay for the medication. Still, sometimes patients would have to make tradeoffs between buying medication for themselves versus for their children, or had other financial priorities. In such situations, the health talks were potentially instrumental in the prioritization of glaucoma treatment – for example, buying glaucoma drops before buying allergy drops, understanding that glasses will not fix glaucoma, or buying glaucoma drops versus spending the money elsewhere.

The inability to pay for medication varied according to the location of the outreach. In one rural location visited, 7 out of 37 patients whom I observed said they were not able to buy medication (I did not ask the patients directly – I simply observed patients as they interacted with the medication dispenser at the outreach). At much larger outreaches in more urban areas, however, I observed almost no people claiming to be unable to purchase medication, and patients would buy additional bottles of medication to have for the next few months. However, most outreaches were to rural areas, where the former situation was much more likely. Another intersecting factor (other than rural location and its connection to income) was age. Patients who were young were often asymptomatic, and thus saw no benefit to glaucoma treatment:

> One was a 19-year-old male with glaucoma, but was asymptomatic. He said he did not have any money for the medication and laughed at [the nurse] when she tried to explain how important it is that he asks his parents for the money. Another 16-year-old male glaucoma patient simply did not have the money for the eye drops either. (Ghana Blog, July 22nd, 2013)

Another structural and economic barrier to glaucoma care was the distance traveled to the outreach. While distance traveled to outreach was a barrier to diagnosis for the undiagnosed, it was also a barrier to glaucoma treatment for returning patients who must travel great distances to obtain a glaucoma check-up or a new bottle of medication.

Psychological/Socio-Cultural

One big barrier to the treatment of glaucoma was that many patients arrived late to the outreaches, sometimes missing part or all of the health talk. It was routine for only half of the patients (or fewer) to be there upon the beginning of the health talk. This frustrated one of the optometrists immensely, because such patients would not understand the glaucoma diagnosis and would not understand the importance of treatment:

> [The optometrist] was extremely upset at the turnout, because we left Kumasi at 6:30am and arrived [at the outreach location] at 9:30am – a three-hour drive. One of the community members said that people were busy because there were several funerals going on in the past few days, but [the optometrist] would not take this as an excuse – she said that this

> meant choosing a funeral over one's own eye health. (Ghana Blog, July 29th, 2013)

Those who did attend the health talk had the opportunity to not only learn about glaucoma but also to observe patients who already completed treatment (typically cataract surgery) and hear them testify about their positive outcome. In terms of glaucoma, returning patients (who were often blind or having severe vision loss) or newly discovered advanced glaucoma cases were used as an example for the asymptomatic patients to understand the importance of glaucoma treatment. One such case was used to show the importance of glaucoma treatment to the two asymptomatic young men – aged 19 and 16 – mentioned on the previous page:

> There was a 28-year-old male with advanced glaucoma. He had the ability only to detect hand motions with one eye and had 6/60 vision in another eye... He bought 2 bottles of Lavamol (glaucoma drops) to prevent his eyesight from deteriorating further. (Ghana Blog, July 22nd, 2013)

Unfortunately, despite this example, the young men were not able to purchase the medication and took prescription slips with the eye drop information on them. This inability (or declining) to buy medication brings into question the effectiveness of the health talk as well.

Another psychological and socio-cultural barrier to glaucoma care is the previously mentioned belief that asymptomatic conditions are harmless and that eye drops are not particularly effective compared to eyeglasses. Eye drops, which are the way to treat glaucoma, were perceived to be less efficacious than glasses, and I often observed

patients who were unable to purchase both their prescribed glasses and eye drop medication wanting to purchase only the glasses, even as the medication may have been for glaucoma. Thus, in choosing treatment, this tradeoff was made by some patients:

> Some patients bought reading glasses, but not the medication; [one of the workers] said that most of the patients who didn't buy the medication simply said they don't have the money for it and sometimes see glasses as an instant fix, and don't see the medication as necessary or effective. [The optometrist] tries to convey the importance of medication in the health talks, and the volunteers even do a demonstration of how to put in eye drops properly, but some of the patients are not present for [the health talk]. (Ghana Blog, July 26th, 2013)

Additionally, even if the patients are present for the health talk, there is no way to be certain that patients paid attention or understood the content being presented during the talk. One optometrist in Ghana used visuals (such as a diagram of the eye) to explain glaucoma, while others spoke verbally about the disease, and this, for example, may affect patient understanding of the health talk.

Thus, the psychological and socio-cultural barriers to glaucoma treatment combine with structural/economic issues, having components of lack of health education, underestimation of the seriousness of asymptomatic conditions, and preference for glasses versus eye medication, along with a limited amount of money to pay for glaucoma treatment and eye care in general. All of these contribute to the barriers to glaucoma treatment from the patient's perspective. Additionally, psychological and

socio-cultural barriers make subsidizing glaucoma medication controversial, as it is argued that patients who do not pay, or pay less, for their glaucoma medication will not value it as much and will not use the medication, especially with the other existing psychological and socio-cultural barriers (Unite For Sight, 2014).

The last barrier to treatment was the language barrier in every direction – not only between the foreign volunteers and local clinic workers and patients. During outreaches to the Nzema region, for example, many patients spoke Nzema and not Twi, so that the optometrists had a difficult time giving the health talk and treating each patient. Additionally, patients came from Cote d' Ivoirian refugee camps in western Ghana, and spoke only French. On a particularly busy day, the outreach volunteers and workers would find themselves "translating in every possible direction – French to and from English, Twi to and from English, Nzema to and from Twi, and French to and from Twi." It is certain that such language barriers would impact treatment.

Qualitative Discussion

The information from the qualitative data was separated into the three components needed for successful glaucoma care – understanding of prevalence, obtaining a diagnosis, and obtaining treatment. For each one, barriers existed that were structural/economic or psychological/socio-cultural in nature, and these were further identified as program-side or patient-side and were different by country. See Figure 4 for a summary of the qualitative findings.

In terms of understanding prevalence, barriers were mostly program-side, particularly a lack of research emphasis on glaucoma by Unite For Sight. Additionally,

lack of population-based research studies on glaucoma prevalence by other organizations and entities reinforced this barrier. Such a lack of research emphasis was structural/economic at Unite For Sight partner clinic outreaches, in that the lack of recordkeeping made research on glaucoma prevalence impossible. Barriers to understanding prevalence were also psychological/socio-cultural from the program-side, as it depended on who decided and framed the important research questions. From the patient-side, understanding prevalence fell through when patients did not attend health talks or did not have eye care knowledge through other sources. The quantitative component of this research hopes to contribute knowledge to the understanding of glaucoma prevalence at UFS outreaches in Ghana.

In terms of obtaining a diagnosis, barriers were evenly distributed between the program and the patient, and were both structural/economic and psychological/socio-cultural in nature. In terms of structural/economic barriers from the program-side, outreaches were poorly distributed, required payment to support the community liaisons, and in India, referred patients to an ophthalmologist rather than providing diagnosis during outreaches. In terms of psychological/socio-cultural barriers, program-side barriers included different emphasis on glaucoma by different clinic employees, which translated to an impact on diagnosis rates. In terms of structural/economic barriers from the patient-side which prevented diagnosis, patients had to travel far to outreaches to get diagnosed, had economic or other opportunity costs, and had to pay to participate at some outreaches. Psychological/socio-cultural patient-side barriers working against diagnosis included the location of outreaches in churches, other social obligations in place of the

outreach, preferring glasses over eye medication, and language barriers between staff/volunteers and patients. However, barriers to diagnosis were also ameliorated or reduced with the use of the health talk to educate patients (in Ghana), and the use of comprehensive screening methods (in Ghana) to ensure glaucoma diagnosis during outreach.

In terms of obtaining treatment, barriers were likewise distributed as either structural/economic or psychological/socio-cultural and at the program or patient-side. Program-side structural/economic barriers to treatment included infrequency of outreaches, differing advertisement methods depending on changing community liaisons, "siloing" of programs and lack of focus on glaucoma (particularly in India), and lack of program subsidy of glaucoma medication for the most needy. Program-side psychological/socio-cultural barriers included individual-level attitudes or emphasis on glaucoma treatment among clinic employees or volunteers. Patient-side structural/economic barriers to treatment included the inability to afford medication or to travel to an outreach for a repeat checkup; psychological/socio-cultural barriers included misunderstanding of the purpose of medication and emphasis on glasses, misinformed attitude toward asymptomatic conditions and glaucoma distribution by age, and language barriers between patients and clinic staff. Health talks helped reduce some of the patient-side barriers to treatment in Ghana.

Limitations

The limitations of the qualitative aspect of this research cannot be overstated. The source of data is purely from my own blogs and observations. No formal interviews were conducted, so systematic information from each location and each individual encountered

is not available, although I tended to ask the same types of questions everywhere given my general healthcare background and global health training provided by Unite For Sight before departure. Additionally, my blogs from Ghana were not geared towards studying glaucoma – I decided on this thesis after I wrote the blogs – so my research on glaucoma in Ghana may have been much more rigorous if I would have planned the research ahead of my travel abroad. Additionally, my interpretation of the situation in India was filtered through the lens of the experience in Ghana, and this certainly may have biased my blog/ observations and analysis. Even if the qualitative information was gathered more systematically, the information is still only based on barriers to glaucoma care witnessed via the work of one organization, working with a few partner clinics and with a certain geographic region in Ghana and India. Thus, these barriers to glaucoma care are not to be extrapolated to barriers to care in the entire Ghanaian or Indian population, or not even to patients attending non-profit outreaches. This is simply research looking at the work of one organization and its partner clinics and only at one snapshot in time. It is important to note that no single patient experienced all of the above barriers to glaucoma care. Instead, these barriers are a description of the potential barriers inherent to the system, and differ across patients and across time.

Additionally, the cultural limitations of being an American researcher in Ghana or India are huge. My ability to know what was going on around me at all times was limited in that I spoke neither Twi nor Tamil, and some of the information I learned was thus gleaned through translation or explanation. My interpretations of issues that are psychological or socio-cultural in nature are prone to error, and I do not have a complete

grasp of the healthcare systems of Ghana and India to fully be able to comprehensively synthesize the barriers to glaucoma care. I do not know all the inner workings of the partner clinics and Unite For Sight, and cannot definitively articulate the program-side structural and economic barriers to care. Thus, barriers to glaucoma care at each level may be overstated, understated, missing, or misreported due to lack of information and because of my interpretation as a foreigner. I hope this thesis is read with these limitations in mind.

Conclusion

The high prevalence of glaucoma at Unite For Sight outreaches in Ghana, combined with the various barriers to glaucoma care in Ghana and India, illustrate that much work needs to be done to successfully care for glaucoma patients living in low-resource environments. The qualitative research highlights areas of improvement for UFS as well as other non-profit organizations doing such work – particularly program-side structural changes that may improve glaucoma care. Additionally, patient-side barriers are important to study, as program-side changes address only one side of the barriers. The quantitative information shows that age and having symptoms are not related to a glaucoma diagnosis, so that it is important to take a comprehensive approach at screening all eye care patients for glaucoma. Another key lesson learned from this research is that location-specific analysis is very important. Extrapolating prevalence from one location to another is inappropriate, and attempting to reduce barriers in the same way across all localities may be counterproductive. Overall, understanding certain principles such as the need for better prevalence research and awareness, access to diagnosis, and access to

treatment should drive decisions for organizations doing work on glaucoma. Otherwise, disparities in access to eye care, particularly for lifelong, complicated conditions, will continue to increase.

The non-profit emphasis of this work shows how important the non-profit sector is in delivering eye care, and that this sector should be studied more to understand how glaucoma care can be better delivered. While this research is specific to an organization and future organizational research is important, additional research on this issue should take up the great task of better understanding the prevalence and barriers to diagnosis and treatment of glaucoma in all populations using other eye care delivery methods (governmental hospitals, the private sector, etc.). Further research on barriers to glaucoma care should be translated into concrete policy changes by organizations, communities, governments, and international institutions. Such translational research is crucial if attempting to truly address disparities and reduce the number of people with glaucoma who may otherwise become blind from the disease.

References

Abdull, Mohammed. 2012. "Patients and glaucoma: what are the challenges?" *Community Eye Health Journal* 25(79-80):44-45.

Al-Hassan, Issah. 2013. "Ghana: World Glaucoma Month Launched in Kumasi." *AllAfrica.* January 14. Retrieved October 31 2013. (http://allafrica.com/stories/201301142083.html)

Balo, Patrice K., G.A. Serouis, M. Banla, K. Agla, P.A. Djagnikpo, K.B. Koffi Gue. 2004. "Knowledge, Attitudes and Practices Regarding Glaucoma in the Urban and Suburban Population of Lome (Togo)." *Sante* 14(3):187-191.

Bowen, Trenton J. 2011. "Assessing the Value of Preventive Ophthalmologic Care in Ghana." *University of British Columbia Medical Journal* 3(1):17-19.

Budenz, Donald L., Keith Barton, Julia Whiteside-de Vos, Joyce Schiffman, Jagadeesh Bandi, Winifred Nolan, Leon Herndon, Hanna Kim, Graham Hay-Smith, and James M. Tielsch. 2013. "Prevalence of Glaucoma in an Urban West African Population." *JAMA Opthalmol* 131(5):651-8.

Centers for Disease Control and Prevention. 2013. *Social Ecological Model.* Retrieved April 8, 2014. (http://www.cdc.gov/cancer/crccp/sem.htm)

Damji, Karim F. "Strengthening institutional capacity for glaucoma care in Sub-Saharan Africa." *Middle East Afr J Ophthalmol* 20:107-10.

De Souza, Nielsen, Yu Cui, Stephanie Looi, Prakash Paudel, Lakshmi Shinde, Krishna Kumar, Rajbir Berwal, Rajesh Wadhwa, Vinod Daniel, Judith Flanagan, and Brien Holden. 2012. "The role of optometrists in India: An integral part of an eye health team." *Indian Journal of Ophthalmology* 60(5):401-405.

Egbert, Peter R. 2002. "Glaucoma in West Africa: A Neglected Problem." *British Journal of Ophthalmology* 86:131-132.

Gwalani, Payal. 2014. "Beware of glaucoma – the silent thief of sight." *The Times of India*, March 10. Retrieved April 7, 2014. (http://timesofindia.indiatimes.com/city/nagpur/Beware-of-glaucoma-the-silent-thief-of-sight/articleshow/31764062.cms)

George, Ronnie, Hemamalini Arvind, M. Baskaran, S.Ve Ramesh, Prema Raju, and Lingam Vijaya. 2010. "The Chennai glaucoma study: prevalence and risk factors for glaucoma in cataract operated eyes in urban Chennai." *Indian Journal of Ophthalmology* 58(3):243-5.

Ghana Embassy. 2013. "Language and Religion." Retrieved October 31, 2013. (http://www.ghanaembassy.org/index.php?page=language-and-religion)

Gyasi, Michael, W. Amoako, and M. Adjuik. 2010. "Presentation Patterns of Primary Open Angle Glaucomas in North Eastern Ghana." *Ghana Medical Journal* 44(1):25-30.

Herndon, Leon, Pratap Challa, Ben Ababio-Danso, John Boateng, Bob Broomer, Philip Ridenhour, and Rand Allingham. 2002. "Survey of Glaucoma in an Eye Clinic in Ghana, West Africa." *Journal of Glaucoma* 11(5):421-425.

ICO. 2013. "Number of Ophthalmologists in Practice and Training Worldwide." *International Council of Ophthalmology*. Retrieved October 17, 2013. (http://www.icoph.org/ophthalmologists-worldwide.html)

ICEH (The International Centre for Eye Health). 2012. "Primary Open-Angle Glaucoma." *Community Eye Health* 25(79-80):41-84.

Jacob, A., R. Thomas, S.P. Koshi, A. Braganza, J. Muliyil. 1998. "Prevalence of primary glaucoma in an urban south Indian population." *Indian Journal of Ophthalmology* 46(2):81-6.

Klip, Ashley. 2010. "Seeing Past the Symptoms: Medical Narratives of Ghanaian Eye Patients." *Dietrich College Honors Theses*. Paper 64. Retrieved October 31, 2013. (http://repository.cmu.edu/hsshonors/64/)

Kyari, Fatima, Mohammed M. Abdull, Andrew Bastawrous, Clare E. Gilbert, and Hannah Faal. 2013. "Epidemiology of Glaucoma in Sub-Saharan Africa: Prevalence, Incidence and Risk Factors." *Middle East African Journal of Ophthalmology* 20(2):111-125.

Lacey, Jenny, H. Cate, and D.C. Broadway. 2009. "Barriers to Adherence with Glaucoma Medications: A Qualitative Research Study." *Eye* 23:924-32.

Lee, Paul R. John G. Walt, John J. Doyle, Sameer V. Kotak, Stacy J. Evans, Donald L. Budenz, Philip P. Chen, Anne L. Coleman, Robert M. Feldman, Henry D. Jampel, Jay L. Katz, Richard P. Mills, Jonathan S. Myers, Robert J. Noecker, Jody R. Piltz-Seymour, Robert R. Ritch, Pail N. Schacknow, Janet B. Serle, and Gary L. Trick. 2006. "A Multicenter, Retrospective Pilot Study of Resource Use and Costs Associated with Severity of Disease in Glaucoma." *Archives of Ophthalmology* , 12-19.

Lee, David A. and Eve J. Higginbotham. 1999. *Clinical Guide to Comprehensive Ophthalmology*. 1st ed. New York: Thieme Medical Publishers.

Lowcountry Eye Specialists. 2014. *What is Glaucoma?* Retrieved April 7, 2014. (http://lceyes.com/glaucoma/)

Mansberger, Steven L., Christina R. Sheppler, Tina M. McClure, Cory L. VanAlstine, Ingrid L. Swanson, Zoey Stoumbos, William E. Lambert. 2013. "Psychometrics of A New Questionnaire to Assess Glaucoma Adherence: The Glaucoma Treatment

Compliance Assessment Tool." *Transactions of the American Ophthalmological Society* 111:1-16.

Morris, Meghan D., Steve T. Popper, Timothy C. Rodwell, Stephanie K. Brodine, and Kimberly C. Brouwer. 2009. "Healthcare Barriers of Refugees Post-resettlement." *Journal of Community Health* 34: 529-538.

Murdoch, I.E., S.N. Cousens, O.E. Babalola, Y.F. Yang, A. Abiose, and B.R. Jones. 2001. "Glaucoma Prevalence May Not Be Uniformly High in All 'Black' Populations." *African Journal of Medicine & Medical Sciences* 30(4):337-9.

Murthy, G.V.S, Sanjeev K. Gupta, Damodar Bachani, H.K. Tewari, and Neena John. 2004. "Human resources and infrastructure for eye care in India: Current status." *The National Medical Journal of India* 17(3):128-134.

Nayak, Barun K., Quresh B. MAskati, and Rajul Parikh. 2011. "The Unique Problem of Glaucoma: Under-diagnosis and Over-treatment." *Indian Journal of Ophthalmology* 59(Suppl1):S1-S2.

Ntim-Amponsah, C.T., W.M.K. Amoaku, and S. Ofosu-Amaah. 2004a. "Awareness and Knowledge of Glaucoma and Other Diseases Associated with Blindness in a Ghanaian Community." *Nigerian Journal of Ophthalmology* 12(2):50-54.

Ntim-Amponsah, C.T., W.M.K. Amoaku, S. Ofosu-Amaah, R.K. Equsi, R. Idirisuriya-Khair, E. Nyatepe-Coo, and M. Adu-Darko. 2004b. "Prevalence of Glaucoma in an African Population." *Eye* 18:491-497.

Ntim-Amponsah, C.T. 2002. "Visual Loss in Urban and Rural Chronic Glaucoma Patients in Ghana." *Tropical Doctor* 32(2):102-4.

Ogden, Jane. 2007. *Health Psychology: A Textbook*. 4th ed. Buckingham, Great Britain: Open University Press.

Oostenbrink Jan B., Maureen Rutten-van Molken, and Tanya S. Sluyter-Opdenoordt. 2001. "Resource use and costs of patients with glaucoma or ocular hypertension: a one-year study based on retrospective chart review in the Netherlands." *Journal of Glaucoma* 10(3):184-191.

Oxfam International. 2011. *Achieving a Shared Goal: Free Universal Health Care in Ghana.* Retrieved October 31, 2013. (http://www.oxfam.org/sites/www.oxfam.org/files/rr-achieving-shared-goal-healthcare-ghana-090311-en.pdf)

Picciani, Renata, Richard K. Lee, and Jeffrey D. Henderer. 2011. "Is Glaucoma Screening Worthwhile?" *Glaucoma Today* Early Spring 2011: 45-46.

Poole, Robert M. 2007. “The Ethiopia Campaign.” *The Carter Center*. Retrieved April 23, 2014. (http://www.cartercenter.org/documents/smithsonian_ethiopia_campaign.pdf)

Porter, Michael E., Paul E. Farmer, and Kim Yong Kim. 2008. “Redefining Global Health Care.” *The Centennial Global Business Summit Report,* 2-5. Retrieved April 1, 2014. (http://www.hbs.edu/centennial/businesssummit/healthcare/redefining-global-health-care.pdf)

Raychaudhuri, A., S.K. Lahiri, M. Bandyopadhyay, P.J. Foster, B.C. Reeves, and G.J. Johnson. 2005. “A population based survey of the prevalence and types of glaucoma in rural West Bengal: the West Bengal Glaucoma Study.” *British Journal of Ophthalmology* 89:1550-1564.

Robin, Alan L., Praveen K. Nirmalan, Ramasamy Krishnadas, Rengappa Ramakrishnan, Joanne Katz, James Tielsch, Ravilla D. Thuladiraj, and David S. Friedman. 2004. “The utilization of eye care services by persons with glaucoma in rural south India.” *Trans Am Ophthalmol Soc* 102:47-56.

Schwab, Larry. 2007. *Eye Care in Developing Nations*. 4th ed. London, Great Britain: RC Press.

Sleath, Betsy L., R. Krishnadas, Minhee Cho, Alan L. Robin, Rakhi Mehta, David Covert, and Gail Tudor. 2009. “Patient-reported barriers to glaucoma medication access, use, and adherence in southern India.” *Indian Journal of Ophthalmology* 57(1):63-68.

Tenkir, Addis, Berhan Solomon, and Amare Deribew. 2010. “Glaucoma awareness among people attending ophthalmic outreach services in Southwestern Ethiopia.” *BioMed Central Ophthalmology* 10(17):1-6.

The New York Center for Health Workforce Studies. 2006. “The United States Health Workforce Profile.” *School of Public Health, University of Albany.* Retrieved October 17, 2013. (http://www.albany.edu/news/pdf_files/U.S._Health_Workforce_Profile_October2006_11-09.pdf)

Thomas, Ravi. 2012. “Glaucoma in Developing Countries.” *Indian Journal of Ophthalmology* 60(5):446-450.

Thompson, Nicholas. 2002. “Self-Adjusted Glasses Could Be Boon to Africa,” *The New York Times,* December 10. Retrieved October 17, 2013. (http://www.nytimes.com/2002/12/10/health/self-adjusted-glasses-could-be-boon-to-africa.html?src=pm)

Trinity University Royal Institute for Deaf and Blind Children. 2014. “Definitions, Identification, and Supportive Professionals.” *Teaching Students with Sensory Impairments.* Retrieved February 27, 2013. (http://www.trinity.edu/org/sensoryimpairments/VI/DIP/dip_toc.htm)

UFS (Unite For Sight). 2013a. “Ghana Program Details.” *Unite For Sight*. Retrieved October 9, 2013. (http://www.uniteforsight.org/volunteer-abroad/ghana/accra)

UFS (Unite For Sight). 2013b. “Unite For Sight: A Trusted Global Health Solution.” *Unite For Sight*. Retrieved October 31, 2013. (http://www.uniteforsight.org/about us/timeline)

UFS (Unite For Sight). 2013c. “Recent Research By Global Impact Fellows.” *Unite For Sight*. Retrieved April 24, 2014. (http://www.uniteforsight.org/global-impact-lab/past-research)

UFS (Unite For Sight). 2014. “Module 2: Eliminating Patient Barriers to Care.” *Online Global Health Course*. Retrieved April 8, 2014. (http://www.uniteforsight.org/volunteer-abroad/training/ethics-quality-equality/module2)

Verrey, J., A. Foster, R. Wormald, and C. Akuamoa. 1990. “Chronic Glaucoma in Northern Ghana – A Retrospective Study of 397 Patients.” *Eye* 4:115-120.

Vijaya, Lingam, Ronnie George, Pradeep G. Paul, Mani Baskaran, Hemamalini Arvind, Prema Raju, S.Ve Ramesh, Govindasamy Kumaramanickavel, and Catherine McCarty. 2005. “Prevalence of open-angle glaucoma in a rural south Indian population.” *Invest Ophthalmol Vis Sci* 46(12):4461-7.

WGA. 2013. *The First African Glaucoma Summit.* Retrieved April 23, 2014. (http://www.worldglaucoma.org/AfricaSummit/pages/africa.php)

WHO. 2013. “Prevention of Blindness and Visual Impairment: Priority Eye Diseases.” *World Health Organization*. Retrieved October 9, 2013. (http://www.who.int/blindness/causes/priority/en/index7.html)

WHO. 2004. “VISION 2020 Priority Eye Diseases.” *World Health Organization.* Retrieved October 31, 2013. (http://www.who.int/ncd/vision2020_actionplan/documents/V2020priorities.pdf)

World Bank. 2012. *Ghana Data*. Retrieved October 27, 2013. (http://data.worldbank.org/country/ghana)

Zelefsky, Joseph R. and Robert Ritch. 2010. “Alternative and Non-traditional Treatments of Glaucoma.” *The Glaucoma Book.* New York: Springer.

Appendix

	Number of Cases	Percent of Sample
25 and under	179	18.47%
26-49 years	305	31.48%
50 and older	485	50.05%
Total	969	100%

Table 1: Age Distribution of Patient Population, 3 Categories

	Number of Cases	Percent of Sample
19 years and under	128	13.59%
20-29 years	85	9.02%
30-39 years	97	10.30%
40-49 years	174	18.47%
50-59 years	174	18.47%
60-69 years	124	13.16%
70-79 years	117	12.42%
80 years and above	43	4.56%
Total	942	100%

Table 2: Age Distribution of Patient Population, 8 Categories

	Male	Female	Sig.
Total	43.14%	56.86%	
By Three Age Categories			***
25 and under	21.77%	15.97%	
26-49 years	33.49%	29.95%	
50 and older	44.74%	54.08%	
Total	100%	100%	
By Six Age Categories			*
29 and under	24.64%	19.96%	
30-39 years	10.77%	9.44%	
40-49 years	19.86%	16.52%	
50-59 years	17.22%	18.51%	
60-69 years	12.20%	13.25%	
70 and older	15.31%	22.32%	
Total	100%	100%	

Table 3: Age & Sex Distribution of Patient Population. N=942. ***p<0.01, **p<0.05, *p<0.1.

	Right Eye (VAR)	Left Eye (VAL)
6\6	42.41%	38.29%
6\9	13.31%	16.31%
6\12	8.67%	9.59%
6\18	5.16%	5.68%
6\24	4.85%	4.85%
6\36	6.40%	5.05%
6\60	3.61%	3.10%
CF5M	0.62%	0.10%
CF4M	0.41%	0.93%
CF3M	1.34%	1.14%
CF2M	1.14%	1.03%
CF1M	2.48%	2.79%
Hand Motions	2.79%	4.85%
Perceiving Light	0.41%	0.31%
Not Perceiving Light	2.27%	1.86%
Child	4.12%	4.02%
Total	100%	100%

Table 4: Visual Acuity of Patient Population. Red=legally blind.

Diagnosis	Percent of Sample
Allergies	48.61%
Glaucoma	**28.17%**
Presbyopia	27.45%
Cataract	11.25%
Suspicious Disc	8.46%
Refractive Error	4.33%
Pterygium	2.99%
Phakia	2.27%
Immature Cataract	1.75%
Macular Scar	1.44%
ARMD	1.14%
Corneal Scarring	0.83%
Traumatic Glaucoma	0.52%
Macular Degeneration	0.21%
Total	139.42%

Table 5: Prevalence of Diagnoses in Patient Population.

	Total	Glaucoma Present	Glaucoma Absent	Sig.
		Mean	*Mean*	
Age (years)	47.79	51.10	46.50	***
	(21.82)	(20.03)	(22.37612)	
Age (3 categories)		*Percent*	*Percent*	*
	25 and under	21.23%	78.77%	
	26-49 years	28.85%	71.15%	
	50 and older	30.31%	69.69%	
Age (8 categories)		*Percent*	*Percent*	*
	19 years and under	15.62%	84.38%	
	20-29 years	30.59%	69.41%	
	30-39 years	27.84%	72.16%	
	40-49 years	30.46%	69.54%	
	50-59 years	27.59%	72.41%	
	60-69 years	30.65%	69.35%	
	70-79 years	30.77%	69.23%	
	80 years and above	37.21%	62.79%	

Table 6: Glaucoma & Age Distribution, using t-test and chi-square.
N=969. ***p<0.01, **p<0.05, *p<0.1.

	Number of Patients	Percent of Sample	Percent with Glaucoma ***
Fetentaa	142	14.65%	20.42%
Apampatia	100	10.32%	35.00%
Asemase	94	9.70%	38.30%
Asamang	93	9.60%	38.71%
Kwanwoma	93	9.60%	15.05%
Jini Jini	80	8.26%	35.00%
Techimantia	72	7.43%	30.56%
Botokrom	61	6.30%	24.59%
Konkuli	54	5.57%	24.07%
Wiamoase	50	5.16%	28.00%
Derma	41	4.23%	31.71%
Barekumaa	36	3.72%	16.67%
Amanfrom	32	3.30%	21.88%
Atimatim	21	2.17%	23.81%

Table 7: Glaucoma by Village/Outreach Location
N=969. ***p<0.01, **p<0.05, *p<0.1.

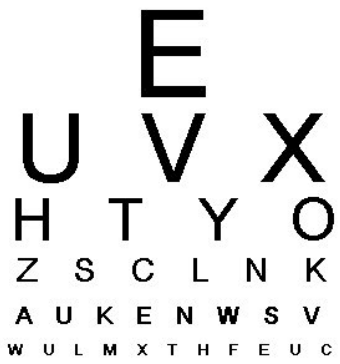
	29 and under	30-39 years	40-49 years	50-59 years	60-69 years	70 and older	Total	Village Glaucoma Prevalence
Amanfrom	40.62%	12.50%	15.62%	9.38%	12.50%	9.38%	100%	21.88%
Apampatia	35%	7%	20%	20%	11%	7%	100%	35%
Asamang	12.90%	2.15%	13.98%	**21.51%**	**21.51%**	**27.96%**	100%	**38.71%**
Asemase	26.60%	7.45%	17.02%	15.96%	14.89%	18.09%	100%	38.30%
Atimatim	38.10%	9.52%	9.52%	19.05%	23.81%	0%	100%	23.81%
Barekumaa	16.67%	11.11%	25%	13.89%	5.56%	27.78%	100%	16.67%
Botokrom	11.48%	3.28%	29.51%	26.23%	6.56%	22.95%	100%	24.59%
Derma	21.95%	19.51%	14.63%	4.88%	19.51%	19.51%	100%	31.71%
Fetentaa	21.83%	22.54%	17.61%	19.01%	7.04%	11.97%	100%	20.42%
Jini Jini	16.25%	10%	22.50%	22.50%	8.75%	20%	100%	35%
Konkuli	27.78%	3.70%	11.11%	12.96%	20.37%	24.07%	100%	24.07%
Kwanwoma	22.58%	10.75%	22.58%	**15.05%**	**9.68%**	**19.35%**	100%	**15.05%**
Techimantia	16.67%	5.56%	13.89%	22.22%	12.5%	29.17%	100%	30.56%
Wiamoase	12%	10%	10%	14%	20%	34%	100%	28%

Table 8: Age Distribution by Village/Outreach; Age Dist. and Glaucoma Prevalence Bolded

	Right Eye ***	Left Eye ***
6\6	23.60%	26.42%
6\9	31.01%	29.11%
6\12	44.05%	31.18%
6\18	30.00%	29.09%
6\24	34.04%	29.79%
6\36	24.59%	28.57%
6\60	20.00%	33.33%
CF5M	50.00%	100.00%
CF4M	0%	33.33%
CF3M	30.77%	36.36%
CF2M	45.45%	1.47%
CF1M	41.67%	18.52%
Hand Motions	44.44%	44.68%
Perceiving Light	50.00%	66.67%
Not Perceiving Light	45.45%	33.33%

Table 9: Glaucoma Prevalence at Different Acuity Levels. N=969. ***p<0.01, **p<0.05, *p<0.1.

Figure 1: Approximations of Vision with Different Acuities (Trinity University 2014)



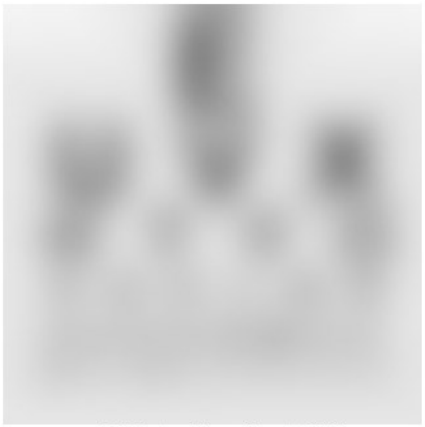
6 Metre Eyechart Normal

6 Metre Eyechart 6/12

6 Metre Eyechart 6/18

6 Metre Eyechart 6/24

6 Metre Eyechart 6/36



6 Metre Eyechart 6/60

Figure 2: Progression of Glaucoma (Lowcountry Eye Specialists 2014)

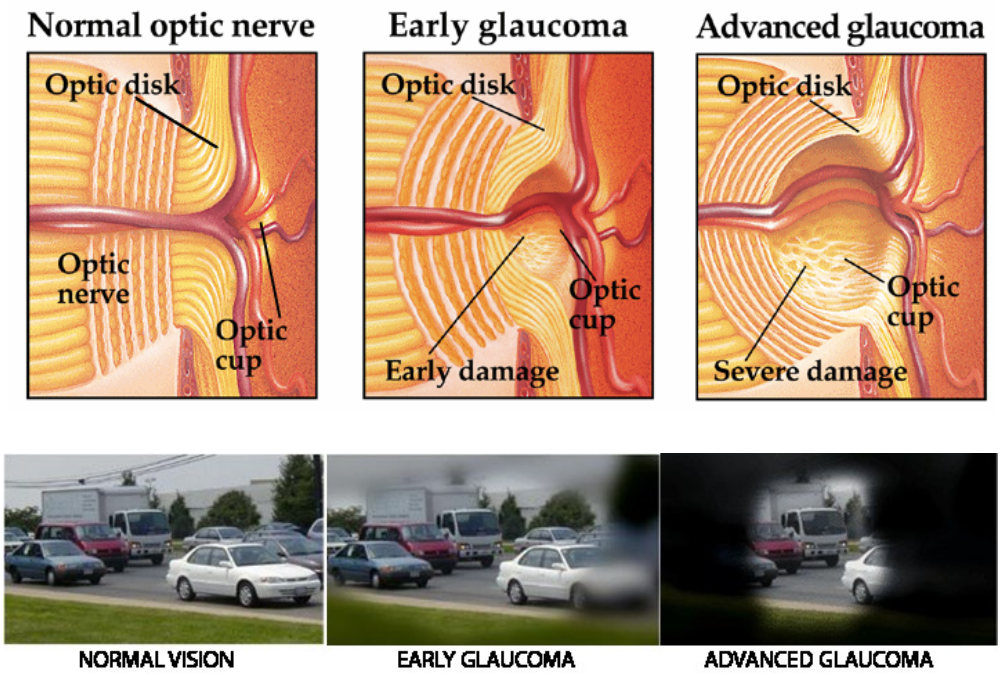


Figure 3: Qualitative Framework

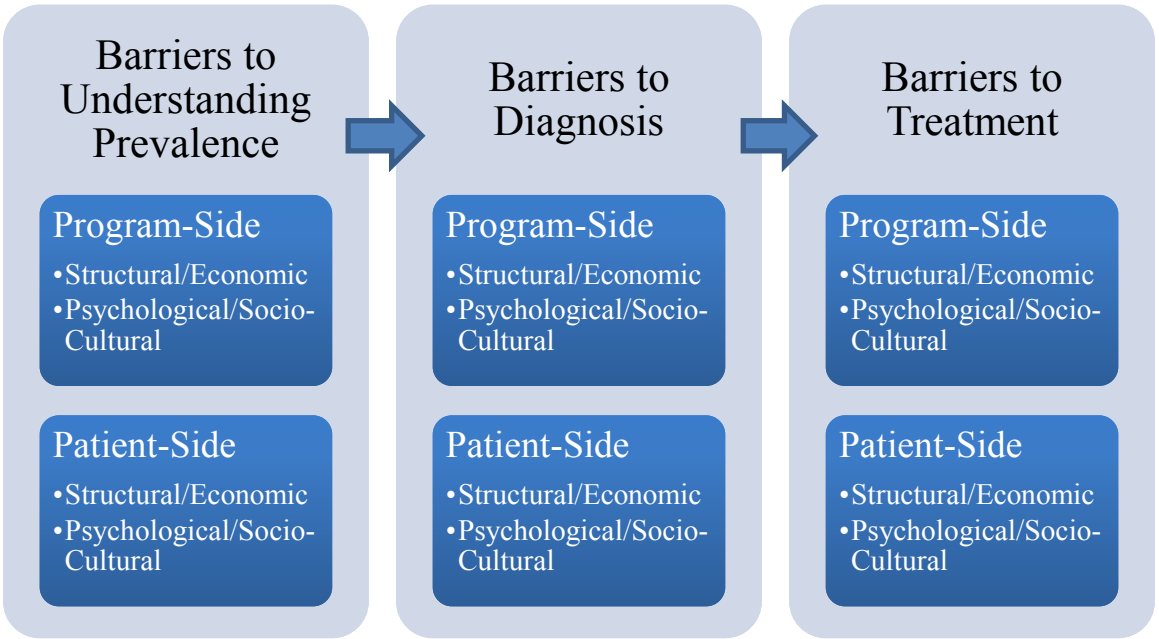


Figure 4: Qualitative Results Summary

Barriers to Understanding Glaucoma Prevalence	*Structural/Economic* • Lack of research on glaucoma by UFS & partner clinics • Poor or no recordkeeping • Lack of research by larger institutions • Reduction: one outreach location keeping longitudinal patient data *Psychological/Socio-Cultural* • Mismatch between who frames research questions versus does outreaches	*Structural/Economic* • Lack of health talk (esp. in Chennai) • Lack of other sources of eye care education *Psychological/Socio-Cultural* • Patients late and miss the health talk • Patients don't pay attention or misunderstand information
Barriers to Glaucoma Diagnosis	*Structural/Economic* • Geographic distribution of outreaches: lack of community connection (in Ghana) or urban-only (in India) • Optometrists not allowed to diagnose glaucoma in India • Referral for diagnosis rather than diagnosis during outreach (in India) • Reduction: comprehensive eye checkups (in Ghana) • Reduction: targeting different areas to maximize diagnosis • Reduction: community liaison assistance, advertising/recruiting, and remuneration *Psychological/Socio-Cultural* • Emphasis on symptomatic diseases, using symptoms (pain, itching, etc.) and visual acuity as indicator of illness • Reinforcing idea that 6/6 vision means perfect eye health (in India) • Different emphasis on glaucoma depending on eye care professional • Over- and under-diagnosis, given subjectivity of nerve damage assessment, time constraints, and lack of 2nd opinion • Reduction: emphasizing comprehensiveness to maintain clinic's reputation	*Structural/Economic* • Fee (paid to community liaison) for participating in outreach (in Ghana) • No other accessible, affordable eye care facilities • Cost/distance of traveling to outreach; opportunity cost of participating, esp. waiting time *Psychological/Socio-Cultural* • Asymptomatic and early onset – difficulty accepting diagnosis (in Ghana) • Location in churches (in Ghana) • Other social obligations (such as funerals, etc.) • Preference for glasses over eye drops • Language barriers between patients and staff/volunteers • Reduction: health talk informed of diagnosis and promoted acceptance (in Ghana)
Barriers to Glaucoma Treatment	*Structural/Economic* • Infrequent outreaches with different community liaisons targeting different communities • Optometrists not allowed to treat glaucoma in India • Medication pricing at outreaches; differing prices • Lack of longitudinal patient data • "Siloing" of program – emphasis on cataract (esp. India) *Psychological/Socio-Cultural* • Clinic employee permission/comfort with giving medication discounts • Emphasis on symptomatic diseases, using visual acuity and symptomology as indicator of illness • Differing levels of passion for treating glaucoma • Reduction: referring to local (versus UFS partner clinic) ophthalmologist for glaucoma treatment (in India)	*Structural/Economic* • Inability to afford medication immediately and in the long-term • Cost of travel to repeat check-ups • Difficulty of accessing an ophthalmologist for glaucoma treatment (in India) *Psychological/Socio-Cultural* • Misunderstanding of glasses versus medication • Attitude toward asymptomatic condition • Belief that glaucoma occurs in older age • Language barriers that hamper treatment • Missing or being late to the health talk that reinforces treatment • Reduction: health talk informed of treatment (in Ghana)
	Program-Side	**Patient-Side**

Vita

Natalya Surmachevska was born in Ivano-Frankivsk, Ukraine and immigrated with her family to the United States when she was nine years old, in third grade. She lived with her family in New York City and went on to attend one of the city's specialized science high schools – Brooklyn Technical High School. She went on to pursue a Bachelor's Degree at Lehigh University, where she majored in International Relations, Economics, and Biology, and got a Certificate in Global Citizenship. During her undergraduate career, she traveled to Ghana, studied abroad for a semester in Hong Kong, and did research in Greece and Peru. She graduated with her bachelor's in 2012 and went on to pursue a Master's Degree in Sociology at Lehigh. She will be attending medical school following graduation from the Master's program, and hopes to work as a physician for the bettering of the American, as well as other countries' healthcare systems.