

**Seeing Past the Symptoms:
Medical Narratives of Ghanaian Eye Patients**

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Abstract

This research examines the interplay of factors that affect health care and health behaviors pertaining to sight in the African nation of Ghana. A series of direct interviews and observations of patients of Unite For Sight's partner eye clinics were conducted. These were used to create medical narratives, in order to elucidate how social, cultural, economic, and political elements contribute to illness incidence, course, and outcome. The efficacy of the medical narrative in this context was evaluated. Additionally, the study explored how determination of the forces that shape the situations these patients find themselves in can bring insight into the efficacy of various methods of providing care, and could greatly impact how the clinics, Unite for Sight, and other NGO's operate.

Introduction

Although often overshadowed by such menaces as malaria and AIDS, an important source of devastation in sub-Saharan Africa and many other parts of the world is preventable blindness. 80% of blindness worldwide is curable or preventable, resulting in 36 million people living needlessly blind.¹ 90% of blind individuals live in low-income countries: in Africa those who are blind have a mortality rate four times higher than the average, and most die within 10 years of becoming blind.² Tragically, 60-80% of children who become blind will die within 1-2 years.³

Having vision is not simply a matter of convenience, particularly in areas where subsistence living is the predominant mode of survival. Blindness and visual impairment prevent individuals from working and contributing to their family's income. About 75% of visually impaired individuals need assistance with simple daily tasks.⁴ The

responsibility of caretaker usually falls to either a sighted adult, who often can no longer work, or to a child, who often must discontinue their education. Often, the impact of eye illness is felt throughout multiple generations and contributes to a continuing cycle: poverty that contributes to bad health that contributes to poverty and so on. As Wagner-Lampl and Oliver write, “The physical and emotional toll impacts not just the individual and family but the social and economic fabric of the communities and everyone’s existence. Sudden blindness of one individual in a family can become the tipping point for survival when they are impoverished to begin with”.⁵ Additionally, there are sociocultural effects: in impoverished countries, half of those blind report a loss of social standing and decision-making authority, with 80% of blind women reporting a loss of familial authority.⁶

Ghanaian ophthalmologist Dr. Seth Wanye describes the situation as follows:

“When we talk about healthcare needs in the government sector, it is all about killer diseases. The government's attention is on these diseases that actually cause immediate death. It is assumed that eye diseases do not kill, resulting in resources being channeled to other areas of healthcare. However...if you have someone who is blind, then someone else will have to forgo his or her activities in order to take care of this person. Oftentimes, you have a child who is supposed to go to school, but he is instead guiding a blind man around the house and directing him wherever he wants to go. This child could have gone to school, study, and become somebody in the future to help the family. We often see very young people who are blind, many times younger than the age of 40. They become blind during their productive years; they could have been working and helping to contribute towards building wealth in the country. Instead, the blindness results in a financial loss to the nation because these people are not able to contribute to building the nation.... We must see this as an emergency issue”.⁷

Health Care In Ghana

Although one of the more stable and developed countries in sub-Saharan Africa, Ghana remains a nation in great need, achieving a Human Development Index ranking of 152 out of 182 countries assessed.⁸ 54% of the citizens survive on less than [price-adjusted] USD \$2 per day⁹, and 30% on less than \$1.25.¹⁰ Life expectancy at birth is only 56.5 years, and the likelihood of death before age 40 is 25.8%.¹¹

Ghanaian health care is a complicated subject. The medical system is an interesting mixture of western-style, scientific medicine that is concentrated heavily in the urban areas and traditional healing that is much more prevalent in the rural population but pervasive in the cities as well. The nation is home to two teaching hospitals, 9 Regional hospitals, 91 District hospitals, and 124 other small hospitals.¹² The teaching hospitals (Komfo Anokye and Korle Bu) and Regional hospitals (located in the regional capitals) are the closest to what might be characterized as “Western-style institutions”. Relatively fully equipped with general and specialized medical personnel, they usually have the capacity to deal with laboratory testing and more complex medical and surgical problems. District hospitals depend heavily on para-medical personnel, nurses, and other health workers, and have difficulty acquiring physicians as full-time personnel¹³. A number of “Health Centres” are also dotted around the country. They are intended to provide routine and urgent care, immunizations, and health education, but these too are rarely permanently staffed by physicians; professional services are provided only on a visiting basis.¹⁴

Traditional healing has been the main mode of medical care for Ghanaians for centuries, and this remains true for a substantial portion of the population. Traditional

healing can be provided through herbal treatments, spiritualistic encounters, and what would be characterized in the Western world as simple “counseling”. Healers can take various forms, but in general they, as Twumasi writes:

“are interested in the whole range of social factors that worry human beings.... [T]raditional medicine takes into consideration social and psychological factors in understanding illnesses. The approach here is holistic. This holistic approach recognizes many other factors in any disease situation than just the physical and natural factors, the preoccupation of modern medicine...No illness is actually cured properly and completely according to the holistic perspective of traditional medicine until the root causes in the individual’s social and economic environment have been dealt with”.¹⁵

The healer is not only the entity who provides diagnosis and treatment; he also serves as an intermediary between his people and the spiritual world.¹⁶ He strives to restore and maintain harmony to the individual and group, with an understanding of the relationships and interdependence of their social unit.¹⁷

It is often easy for health workers of Western medical training to immediately discount the efficacy of traditional medicine, or condemn it as harmful. Although there are definitely some examples of traditional healing that at best do nothing to alleviate the condition and at worst cause harm, a substantial number of our medications today derive from plant compounds first used as traditional treatments. Additionally, traditional healers bring a level of relief and confidence to their clientele that Western practitioners can find hard to match: these healers often know their patients personally, and have cultural history and societal structure on their side. That said, individuals from rural, traditional communities generally do not utilize traditional medicine to the exclusion of Western biomedical practitioners. Often, people will seek care from both, using whichever method is most accessible or promises the best likelihood for healing in that

situation. As Finkler writes, “In the search for the alleviation of pain, pragmatism prevails; people judge the treatments they are given by their effects. They look toward those who provide them with the best medicine for a given sickness episode”.¹⁸

A variety of challenges have been identified by non-governmental organizations working to provide health care. Among these are inability to afford treatment and the inability to find that treatment. In 2002 the entire nation was home to only 43 ophthalmologists, or 1 ophthalmologist per 442,000 people. In a classic case of “brain drain”, that number is dropping as professionals leave the country for better opportunities elsewhere¹⁹, Additionally, Ghana is similar to the US in that it is more lucrative for a physician to be located in a well-equipped, urban hospital and practice a specialty rather than practice primary care.²⁰ Although only 23% of the population lives in urban centers, 42% of physicians working for the government health service work there.²¹

Common Eye Conditions of Ghana

Eye health in particular continues to be a real issue in Ghana. A large number of citizens are blind or visually impaired, most often for treatable or preventable reasons including cataracts, vitamin A deficiency, glaucoma, trachoma, onchocerciasis, trauma, and presbyopia. Understanding of the explanatory models and treatment designs for these diseases depends upon an understanding of the etiology and mechanisms of these conditions; thus, a brief explanation of each follows.

Cataracts occur when the eye’s normally transparent lens becomes cloudy, blocking vision. The condition is generally related to age and sun exposure, although trauma can also be a cause. Barring other eye damage, cataracts can be treated relatively easily with a simple replacement of the lens with a synthetic intraocular lens (IOL), a

surgery that costs less than \$50 and takes less than 15 minutes. Age-related cataracts are responsible for almost half of the world's blindness.²²

Vitamin A deficiency is seen in malnourished children; this nutrient is essential for adequate eye maturation and the lack of it can cause vision to slowly degenerate. The first symptom is usually night blindness, but ultimately the corneas keratinize, erode, and are destroyed, causing complete blindness. If individuals do not obtain adequate Vitamin A in their diets, a simple eye drop every six months during childhood is enough to prevent blindness.²³

Glaucoma is characterized by an increase in pressure within the eye such that the optic nerve becomes damaged. Those of African ethnicity are 6 to 8 times more likely to develop glaucoma than Caucasians.²⁴ It is a "silent" disease, in that there are no outward symptoms, just a gradual loss of vision; by the time patients notice that there is a problem, their glaucoma is usually advanced. Loss of vision is progressive and irreversible; treatments can stop or slow the progress of the condition, but cannot allow vision to be regained.²⁵ Thus, early detection by means of regular intraocular pressure (IOP) readings is key, but this is uncommon in settings such as impoverished rural Ghana. Additionally, the most effective, cheapest treatments are generally medications taken consistently for the remainder of a patient's life, a requirement not feasible in the lives of many Ghanaians.

Trachoma is a bacterial disease that, when left untreated, can deform the eyelids and cause them to turn inwards. This results in scratching and scarring of the cornea by the eyelashes. Trachoma can generally be prevented by improving sanitary conditions, and is treated by antibiotics or surgery in advanced cases.²⁶

Onchocerciasis, also called “River Blindness”, is a parasitic disease transmitted by flies. Due to the nature of the vector, it is much more common near rivers and similar bodies of water.²⁷ It is not actually the worms themselves that cause damage, but the strong immune response elicited upon their death. Sclerosing keratitis occurs on the cornea, eventually turning it opaque. Treatment is via an antibiotic that must be administered over a three-year period; however a recent study in Ghana suggests that the parasite may be becoming resistant.²⁸

Traumatic eye injuries account for a significant proportion of blindness in Ghana. Examples include farming or industrial injuries, trauma induced by traditional medicine, and head injuries. The most common pathology observed is corneal scarring, in which the outer covering of the eye becomes scarred and opaque. Also observed are staphyloma – a protrusion of inner eye tissue through a weak point in the eyeball often resulting from a puncture wound – and cataract and optic nerve damage resulting from head injuries.

Presbyopia, a form of far-sightedness caused by a loss of elasticity in the eye’s lens, is experienced by almost all adults over age 40. All that is needed to correct the resulting refractive error are reading glasses, but these are often unavailable or unaffordable. What is a nuisance for those in developed nations becomes the second most common cause of blindness for those in impoverished nations like Ghana²⁹.

Methods

The Medical Narrative

This study aims to elucidate how exactly Ghanaian eye patients understand their illness, how they have made medical decisions, what they perceive to be the barriers to their care, and particularly to determine whether the collection of “medical narratives” is an effective and appropriate method by which to gather this information. A medical narrative is an individual’s story about their illness, as they understand and experience it. This model was pioneered by Arthur Kleinman, a medical anthropologist and psychiatrist. As he explains:

“patients order their experience of illness – what it means to them and to significant others – as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meaning”.³⁰

The medical narrative has long been a fundamental tool of medical anthropologists, and is now gaining support within the mainstream medical community. Medical school curricula continue to move from the traditional, purely biomedical model of medicine to a broader biopsychosocial model, and are increasingly incorporating the idea of narrative medicine into their MD programs^{31,32,33} or even creating entire programs dedicated to the field^{34,35}. Additionally, a large amount of literature has now been written underscoring the importance of medical narratives for patient healing, including the work of such champions of the model as Rita Charon^{36,37} and others.^{38,39}

Even in this molecular and genomic age, the case for the medical narrative as an important tool is strong. As Kleinman explains, medical narratives can serve as:

“a framework for assuring that the uniqueness of illness as human experience, in all its many social and personal manifestations, becomes the center of the healer’s gaze.... Attempts to formulate complete psychosocial systems of care that claim to answer wholesale each and every one of the serious dilemmas faced by patients, families and clinicians... contain a dangerous hubris.... [Physicians] must recognize that human problems cannot be reduced to simplistic formulas and stereotyped manipulations....”⁴⁰

Additionally, they can provide insight into the cultural construction of illness, helping us to better understand how illness impacts patients’ lives. Furthermore, the medical narrative also allows patients to gain therapeutic advantages by verbalizing their experiences and making sense of them – in a way creating order from disorder.

One way in this occurs is through discovering if and how patients’ understandings of their disease etiologies significantly differ from those of the biomedical world and its personnel. An explanatory model is an individual’s personal interpretation of the etiology, treatment, and outcome of their sickness, and is the mechanism by which he or she gives meaning to the condition.⁴¹ This can have an important impact on how we understand patients, their conditions, and how those patients have made medical decisions. As Glick writes, “the most important fact about an illness in most medical systems is not the underlying pathological process but the underlying cause. This is such a central consideration that most diagnoses prove to be statements about causation, and most treatments, responses directed against particular causal agents”.⁴² Patients’ explanatory models – particularly in non-Western societies – can depart greatly from that of scientific medicine, especially in describing the cause of an illness. Where the western biomedical explanation might involve discussions of germ theory and biological processes with little to no mention of mental, emotional, or social matters, those in a non-Western culture might attribute illness to the active intervention of an angry ancestor, evil

spirit, or bad feeling from another person or to an upset of bodily balance and equilibrium⁴³. Such differences have been documented in many ethnographic and medical anthropological studies. In his book *AIDS and Accusation*, Farmer discusses the explanatory models of Haitian AIDS patients and their families and friends. When asked how and why acquaintances had contracted AIDS, which they called “*sida*”, members of a rural Haitian community produced such explanations as “someone...sent the illness ‘on him’.... ‘It’s a sent sickness that is clear’.... ‘He has very serious, big problems, and it’s no wonder his blood has gone bad.’... Some even spoke of the night, years ago, that [he] had been knocked out of bed by a bolt of lightning. The shock, they said, had left him ‘susceptible’ to *sida*”.⁴⁴ Although in the early years of the AIDS epidemic many of those interviewed had distinctly western views of the illness, i.e. that the disease is transmitted by some sort of “microbe” and is related to homosexuality, these explanations were “soon subsumed...in distinctly Haitian beliefs about illness causation”.⁴⁵

Similarly, there exists in Latin American culture the illness of *susto*, a “culture-bound syndrome” presenting with symptoms of restlessness during sleep, listlessness otherwise, depression, and debilitation. The condition is generally brought on by stressful situations of a societal nature and is attributed to the detachment of the person’s “essence” from the body and its subsequent capture by supernatural forces⁴⁶, an etiology distinctly different from any biomedical explanation. Regarding Africa, Foster writes that the “ethnologist analyzing medical beliefs and practices in an African community can scarcely avoid dealing with witchcraft, oracles, magic, divining, and propitiation”.⁴⁷ As he describes traditional healing in Ghana, Twumasi offers that the people may believe that

“harm may come from a physical accident, from an evil eye, or from a malicious person or even from the proverbial mother-in-law. Why for example, did the married woman fail to bring forth a child? Why do people get sick and why do other people stay well? Social, psychological and physical factors unite in building a coherent paradigm... in explaining health and illness phenomena”⁴⁸.

To disregard patient understandings of disease etiology that depart from those of scientific medicine is to disregard that patient’s illness experience. Particularly in cultures in which health, religion, and social matters are inextricably linked, patient beliefs as to the cause of their illness will impact their medical decision making and must impact how a practitioner should interact with and treat them if an optimal outcome is to be achieved. In eliciting this explanatory model from a patient, the creation of a medical narrative can be crucial.

A second point of usefulness of the medical narrative is in elucidating possible “invisible” barriers to care. Medical personnel are often quick to label a patient who does not follow medical advice as “non-compliant”, but there are frequently unseen issues that prevent those patients from being able to follow that advice. Kleinman describes such a situation: a conversation between a poor, African-American, single mother and the doctor who examines her. His post exam notes describe her as having “hypertension, poorly controlled” and “noncompliance, contributing to [the hypertension]”, and his instructions to the dietician to whom he refers her reads exasperatedly that the patient “does not comply with low salt diet. Please... explain to her again relationship of salt intake to her disease and that she must stop eating high salt foods and cooking with salt”. However, in the transcript of their conversation, the woman continually returns to the enormous pressures of her life, which clearly are preventing her from having the time, resources,

and energy to make these lifestyle changes – a crucial fact to which the doctor is painfully blind.⁴⁹

In *The Spirit Catches You and You Fall Down*, Anne Fadiman tells the poignant story of Lia Lee, a Hmong toddler with severe epilepsy. The child's many doctors express to varying degrees their frustration that, had their instructions been followed more closely, the outcome for Lee would likely have been a much less negative one; at one point, she was even removed from her parent's care on grounds of neglect. However, a closer look into the lives of Hmong immigrants and into the experience of Lia's family in particular reveals significant language barriers; underappreciated, but valid, distrust of western medicine resulting from negative past experiences; and many other cultural roadblocks.⁵⁰ Careful exploration of these issues by Fadiman brings to light what at first glance seem to be obvious failings of the medical personnel that treated Lia; however, her care providers largely acted with the best possible intentions and a great deal of care and compassion. Yet without the benefit of the family's medical narrative, they were unable to interact with them successfully.

Another important lesson gained from the medical narrative is the understanding that disease (a set of physical symptoms) is not synonymous with illness (the lived experience of that disease). How a disease affects patients' lives, livelihoods, and relationships is critical in informing how patients will deal with the illness and make medical decisions. Medical narratives seek to understand the "lived experience" of an ill individual. On a concrete level, illness impacts an individual's ability to interact with the world in the same way or to the same extent as previously: perhaps they can no longer work or hold their child, or they must make difficult choices between optimal care and

other demands of life, or the illness causes others to react differently towards them. Less tangibly, illness can also affect the individual's concept of self and world. As Murphy writes, "the disabled... enter the social arena with a skewed perspective. Not only are their bodies altered, but their ways of thinking about themselves and about the persons and objects of the external world have become profoundly transformed".⁵¹ Additionally, how an individual's social and cultural environments react to and deal with a particular illness informs also how that individual will experience it⁵²: for example, the sociocultural environment of the stigmatized sufferer of leprosy is much different than that of the romanticized "consumptives" (tuberculosis patients) of the nineteenth century, causing important differences in the lived experiences of each group. Insight into a patient's lived experience can also show how sociocultural or economic status may have played a role in inducing (or not preventing) the condition in the first place.⁵³

Finally, medical narratives can be useful in exploring how an individual's illness affects the wellbeing of the family and broader community. Exposure to and observation of an individual's illness, its initiation, and its progression provides others with experiences and information that will affect how they understand and approach that illness with respect to themselves or others in the future. Additionally, if family or community members are acting as caregivers, an individual's illness can have important implications on their occupational and financial situation, as well as their physical, mental, and emotional health.⁵⁴ Issues of how responsibility for care is allocated, and how familial resources are distributed among family members, are important to consider, as is the role of gender.⁵⁵ The health of an individual is also often extended to serve as a

symbol for the health of a family or community, and many societies emphasize “the link between the health or illness of the individual body and the social body”.⁵⁶

For all of these reasons, medical narratives are thought to be a useful and important tool, and were a natural choice for the exploration of the explanatory models and medical decision making of Ghanaian eye patients in this study. This design also provides the opportunity to evaluate the medical narrative itself as a methodology.

Experimental Methods

Fifteen subjects were interviewed: 9 female and 6 male. The mean age was 61.5, with a range of 21 to 84. Subjects were from the Central, Eastern, and Volta regions of Ghana, areas located in the southern central and eastern part of the country. Subjects were almost entirely of extremely low socioeconomic status – the target demographic of the outreach clinics at which they were recruited. Although the national language of Ghana is English, as a result of its history as a British colony, virtually all Ghanaians learn a tribal language as their first language. Since English fluency is highly correlated with education and socioeconomic status, most subjects spoke their local language and were interviewed via an interpreter. The most common languages were Twi, Fante, and Ga, and interviewers were either another community member or a member of the clinic staff.

Each subject was recruited at an outreach clinic conducted in their village or a neighboring one. Interviews were taken after the patients had been examined by the medical staff and treatment had been provided in order to mitigate any feelings of needing to give the “right answers” in order to receive care, as well as to assess the

effectiveness of the clinic's education and counseling efforts. The outreaches were organized and conducted by Crystal Eye Clinic and Save The Nation's Sight Clinic, non-governmental organizations (NGO's) based out of the capital city of Accra. These organizations operate with financial resources and volunteer labor from Unite For Sight, an international NGO whose goal is to eliminate preventable blindness through effective, sustainable programs. While conducting this study, I was also serving as a Unite for Sight Global Impact Fellow at these outreach clinics, helping to register, screen, and provide glasses and medicine to patients.

Hypotheses

Certain findings were expected from the interviews. Subjects were expected to identify financial factors and inability to access a doctor as primary reasons for not getting adequate care. Subjects were also expected to have utilized traditional healing methods and ascribe at least in part to non-Western, non-biomedical explanatory models. They were expected to have strong social support; subjects were expected to benefit from this, but those providing the social support to experience negative effects. Eye disease was expected to cause further financial or health problems for the individual or family. Finally, the medical narrative construct was expected to effectively and as fully as possible provide a clear picture of the cultural construct of eye illness in rural Ghana.

Results

Patient Explanations of Conditions

Each patient interviewed offered some explanation of the nature and etiology of his or her condition. Although these explanations were not always correct by the standards of Western medicine, no individuals lacked a theory of how their malady had arisen. Even if they didn't use medical terminology, a number of individuals (7 of the 15 subjects) did correctly and specifically identify the source of their eye problem, particularly if the cause was trauma or cataract:

“She was playing and fell down, and something hit her in the eye” (Clinic diagnosis: staphyloma caused by trauma).

“[I] went to the farm, and [I] was farming, and all of a sudden, [I] don't know what, something fall on the eye” (Clinic diagnosis: corneal scar).

“There is something like a stone in my eye, and that is what makes me not see again” (Clinic diagnosis: cataract).

“Stones are on my eyes” (Clinic diagnosis: cataract).

However, it was just as common for individuals to cite unrelated traumatic events or illnesses as the cause (8 of the 15 subjects did so). One man explained his impaired vision as being the result of an earlier stroke, rather than his mature bilateral cataracts: “[I] feel the condition (*the stroke*) has affected the eyes”. This explanation was elicited even after examination, counseling, and his consent to cataract surgery. Another man correctly attributed his visual impairment in his right eye to a past trauma, but regarding his left eye stated that “the problem [in the right eye] is trying to affect the other eye too”.

The presence of an explanation, even if incorrect, makes sense from a psychological standpoint. Individuals, when presented with some situation or event, will seek to explain it; if no readily available explanation exists, one will be created using whatever information or past experiences that individual has available. We seek to make sense of the world: unexplained phenomena, particularly those that affect something so central to ourselves as health, are much more terrifying and anxiety-producing when their source is mysterious. Identifying causality and crafting meaning help us to cope.⁵⁷

Notably absent, however, was any mention of non-biomedical causes of illness. In these rural, poor, traditional communities with a culture of the non-scientific explanatory models discussed previously, this was very much unexpected. Similarly, very few individuals admitted use of traditional medicine or healers when asked about it directly. Only 5 of the 15 subjects described any traditional medicine use, and of these only one said he had continued its use: the others emphasized that they “*no longer used it*” or “*stopped a long time ago*”. This was surprising, since even those who believe in biomedical treatment have been shown to utilize traditional healing when it is the only treatment available or accessible. However, when asked if they knew someone who had, or if someone had encouraged them to, most of these subjects responded yes: of the 10 who had “never” used traditional medicine for their eyes, 6 had been advised to do so by someone else. One woman admitted that she used traditional medicine, but emphasized that she never had “for the eye”. Although most subjects directly denied the use of traditional healing, the answers to these alternate questions make suspect the claim that subjects were not utilizing it. If those in the patient’s social and familial groups use

tradition medicine and opportunities to use Western medicine are few or nonexistent, it is very unlikely that the subjects were not using traditional healing at least some times.

If this is the case, subjects were not responding in a fully honest manner when queried directly about particular health behaviors they knew to be out of line with the Western biomedical model. It is easy to understand why this would occur: the presence of demand characteristics⁵⁸, including participants that change their behavior to match what they believe the experimenter wants, is well established, and can be easily translated to the doctor-patient relationship. In this context, participants may have been trying to give the answers that they assumed a Caucasian, American visitor bringing Western medicine to their village would want. Rather than giving their own explanatory model, it is conceivable that some participants could have simply repeated what those conducting the medical exams had told them. As Twumasi writes, “the average Ghanaian who perhaps frequents the traditional medicine man may distort his answers because he ‘knows’ that going to traditional practitioners is not the ‘right’ thing to do”.⁵⁹

Additionally, as one of the volunteers I would have been identified as a health care provider, if not a doctor; in fact, in three of the interviews, I was asked to provide further examination and care, at which point I referred them back to the true medical professionals. Ghanaian medical staff confirmed that they had found it common for patients to deny use of traditional medicine, misuse of Western medication, or trauma that could be construed as “their fault” for fear that they would not be provided with treatment. For example, this was likely the case with a 21-year-old man who suffered from a mature cataract in his left eye. Cataracts are extremely rare at this age unless congenital and the only real explanation for his case was past trauma; however, the

subject would only say that the cataract had developed on its own with no event that he could remember causing it:

“[I] don’t remember anything hitting the eye, [I] only remember that it was painful”.

As much care as possible was taken to mitigate the effects of this problem in the study, including adjusting how questions were worded and presented and increasing emphasis on the separation between their treatment and their answers during the pre-interview briefing. However, since it was impossible to change my appearance and identity, and since I did not have the advantage of time to develop more trusting relationships with my subjects, this limitation was not entirely escapable

Barriers To Care

As expected, the most prevalent barrier to care reported was inadequacy of financial resources: 10 out of the 15 individuals interviewed cited this as their greatest challenge. Subjects found it difficult to impossible to pay for transportation to medical care or for that care if they found it:

“The only problem is the financial difficulties”.

“There is both financial and [finding] the one who will take [me] to the hospital. And because of financial problem [I] can’t go to the hospital, and because there is nobody to take [me] to the hospital”.

“Financial problem has been very difficult”

“It’s money problem. Because I know when you go to the other hospitals they charge very much. They charge huge amount, but, because I don’t have the money, that’s why I didn’t go to any of those places”.

A number of subjects (11 of the 15) discussed previous care that had been provided at hospitals or by other NGO's. In 3 of these cases – all of which were individuals who had gone to a Ghanaian hospital for care – the subjects were examined but then were unable to pay for the treatment.

It was interesting to find, however, that no patients cited non-financial barriers. This is unlikely in any environment, and even more so given the social, cultural, economic, and infrastructural nature of rural sub-Saharan Africa. Known barriers include transportation issues and the inability to find a doctor, and individuals likely had a number of problems specific to their own lives, situations, and families. None of these were articulated.

It seems that the time and methodological constraints of the interviews hindered the collection of full narratives in this domain as well. Any person may feel less than compelled to talk in depth about personal life challenges with someone whom they met less than fifteen minutes previously; in this context, my status as clinic worker and obvious foreignness further compounded the problem. In addition to being distrustful, they may have feared having their care rescinded if the barriers they spoke of could in some way be construed as “their fault”. Fear of stigma regarding some aspect of their explanatory model, the nature of their barriers to care, or their lived sociocultural experience could have also played a role.

Additionally, some difficulty was experienced when asking this question of patients. In multiple instances the subject or the interpreter did not understand what was being asked, and various rewordings of the question had to be tried. In some cases, it was necessary to default to giving examples, e.g. “Have things like money or transportation

made it hard to get care for your eye?” If subjects did not fully understand the question, it is unrealistic to expect rich answers in return. With the subjects for whom it was necessary to use leading questions, it makes sense that they would latch onto one of the suggested issues and expand no farther. Although most subjects seemed to understand the question, the confusion of the others raises the possibility of more pervasive misunderstanding.

Lived Experience of Illness

When asked about the impact on their daily lives, subjects of employment age almost unanimously cited inability to work as one of their greatest burden. 12 of the 15 subjects discussed this, with the other 3 being individuals too elderly to work either in or out of the home:

“[I] am a farmer, [I] cannot do any job [on the farm], so I suffer”

“Because of the eye I cannot work”

“Since [I] got handicapped because of the eye problem, financial problem has been very difficult”.

“[My] profession is driving, and because of the sight [I] can no longer drive”

“Without the eye, she cannot do anything. And [for] the children, who are many, she doesn’t have any help... because the husband is now dead. So she always thinks about the eye”.

(young man who had gone to school to be a driver) *“If [I] can’t drive, there isn’t anyone who can put [me] through another trade... [I] don’t know what [I] will do.”*

Thus, those who were unable to access care were placed into positions in which their income was lowered even further, placing health care and other necessities even further out of reach. Ghana implemented a national health insurance system in 2004, but this program is still in its infancy, with 54% of the country enrolled⁶⁰, and most of these individuals are in or near urban centers rather than the poorer rural regions. This insurance costs less than USD \$1 per a month, but this can still be a prohibitive amount for the extremely destitute, and insurance is useless in those areas where there are no doctors to provide care. Only one subject remarked that, because he had insurance, money was not an issue.

Some patients also offered more personal insight into their visual impairment. One woman had immature cataracts that were not yet ready for surgery, so she had not been given any treatment, only instructions to return to be examined again at a later date. This did not sit well with her:

“[I] want immediate medication...something to cool down the pains.... I don’t want to wait six months”.

Pain, itching, or irritation are not symptoms of a cataract, making it likely that some other eye problem, minor or major, was co-morbid. This situation illustrated very well the benefits of eliciting the patient’s story: while the doctor focused on the observable sight-limiting disease process and prescribed a very appropriate treatment, this was not the primary reason why this woman was there. Better vision would be wonderful, but at that moment pain relief was the most important thing to her, and she was frustrated that this had not been provided to her.

Most of the patients who offered deeper commentaries were happy with their experience at the clinic. One elderly woman explained that she had not sought treatment for her cataracts because she and the others in her family and community perceived her progressive deterioration of sight as a natural result of aging; when asked about how she felt about her upcoming surgery, she replied that afterwards she “*will be living good*”. A man, after acknowledging the negative impact his blindness had on his ability to work, was asked why he had agreed to cataract surgery. Instead of any comment regarding financial or mobility barriers, he responded:

“I cannot see what is beautiful anymore. I can only listen when other people say something is beautiful. So I will get the surgery”.

Even in a destitute, sub-Saharan village, the benefits of sight need not be purely pragmatic. Sight is a crucial part of the human experience, and its loss has mental and emotional consequences that, while not as observable, measurable, or tangible as the physical ones, are as important and tragic.

Social Support

The positive impact of social support on health and wellbeing is well documented. The more extensive an individual’s social circle, the more likely they are to make healthy decisions, take care of themselves, be able to find help if it is needed, and have a more positive outlook^{61,62,63}. In Ghana, the importance of social support is even greater. Ghanaian culture places great importance on the family unit – immediate and extended – and community⁶⁴. This is particularly true in the rural areas.

The subjects were no exception to this rule. All but one of the participants lived with or close by children, a spouse, or other family member(s). These relations often provided assistance with daily tasks or continual care; four of the subjects were actually brought to the clinic by one of these family members.

This being said, social support was not an entirely positive thing in these situations. Although the benefits to the visually impaired subject were obvious – indeed, most would not have survived if not for the aid of their families – this often came at a cost to the caregivers. The negative effects of stress on a caregiver have been documented⁶⁵, but in these cases the impact was even more tangible. As described earlier, loss of vision means that the individual can no longer work and contribute to the family, which results in a decreased labor force but the same number of people for which to provide. In addition, if a caretaker is needed, this often necessitates that an adult stop working if they have a job outside of the home, or they must add this to their many other duties. Often, this means a decreased income, and thus deepening poverty.

Clear examples of this were found. One man, suffering from severe corneal scarring that left him entirely blind, had a wife and two daughters, aged two and three. Because of his disability, he could not support his family; because he could not afford rent, he was living with his mother while his wife and children lived with her family in another part of the village. His blindness had effectively split him from his family, and prevented him from being the caregiver and provider he wanted to be for them. In a particularly striking case, I spoke with one elderly woman and her primary caregiver, her daughter-in-law. When the woman developed cataracts, the family did not have access to surgery; to take care of her, the daughter-in-law stopped working outside of the home and

remained with the woman each day to care for her. Although the woman's son was still providing an income, it was significantly less without the work of his wife. As time progressed, the daughter-in-law began to have vision problems – however, with even less money and no access to eye care, she did nothing. When she heard about the eye clinic that would be coming, the daughter-in-law made certain to get her mother-in-law there; happily, the woman was a great candidate for cataract surgery and was referred for the procedure, which would be completely paid for. However, while they were there the clinic screened the daughter-in-law as well, and discovered that she had moderately advanced glaucoma: irreversible, permanent, and completely preventable vision loss. Had she not needed to stay home to care for her mother-in-law, perhaps she would have had the resources for the simple, quick examination that would have discovered this problem, and the medication that could have stopped its progression. Instead, the visual impairment of one generation played a significant role in the visual impairment of the next.

Methodological Limitations

Translators and Translations

This study has elicited compelling results, but does have some important limitations. One of the most significant was the use of translators and the quality of the subsequent translations. In an interview-based study, even the best translation runs the risk of losing subtle nuances and context in the course of the subject's response. While some translators were better than others, many did not attempt to translate word for word, but most of the time only relayed the gist of the information the participant offered. This was apparent in cases where the subject would speak for an extended period and the

translator's English version was incongruously shorter. Additionally, as detailed earlier, it was clear that some of the questions were not fully understood by the subjects. To craft the best mode of explaining and wording questions to those of a different language and culture requires extended time and exposure to that community, a luxury that was not available.

Another consideration with respect to the translations is that most of the translators were either clinic staff or members of the local community. If subjects did not fully understand their illness or gave important information that had been missed during their examination, clinic staff translators may have worried that this would reflect badly on the clinic. Similarly, community members may want to show that their neighbors understand their condition and treatment, and are grateful for the clinic's presence, as encouragement for the clinic to return to the village. Although it is hoped that the translations were conducted truthfully, there was opportunity for translators to leave out parts of, or add to, the response.

Sample Size

Another issue was a relatively small sample size of 15, a number clearly too small to make sweeping declarations regarding eye care in rural Ghana. The small sample size was necessary, since the primary objective of each outreach was to provide quality care to the greatest number of patients possible; research such as this is a secondary concern, and the time allotted to each is reflective of this prioritizing. With the goal of eliciting thorough, rich narratives rather than a demographic glimpse of each participant, a compromise was attempted between quality and quantity of interviews.

Demand Characteristics

It was also important to understand the patients' responses within the context of the situation and our respective identities. As previously described, in the first few interviews it quickly became apparent that many subjects would make great effort to be seen as "good patients" in the Western context; for example, although the use of local, traditional medicine is prevalent in rural Ghana, when asked directly if they had used it almost all of the subjects replied that they had not. Again, although steps were taken to decrease the effects of this confound, it remained a significant roadblock to obtaining full, honest narratives.

Conclusions and Recommendations

Utility of the Medical Narrative

The vast majority of literature on the subject points to the benefits and utility of this method, with very few taking a critical stance.^{66,67} However, while the medical narratives provided for this study confirmed some hypotheses and highlighted some compelling ideas, in this context the methodology had significant limitations. The motivation of the narrative is to elucidate the patient's explanatory model, the "invisible" barriers to care, the lived experience of illness, and the effects on the broader social circle. The data and its subsequent interpretation showed that the narratives were somewhat effective at discussing the lived experience of illness and social effects. In providing real explanatory models and identifications of barriers, however, the narratives fall quite short. Subjects resisted giving their true beliefs and ideas and instead may have parroted the Western biomedical etiologies they heard from the medical personnel who

examined them. It is conceivable that some of the patients truly believed solely in the scientific medicine model, but the subject demographics make this highly unlikely. Additionally, the suspicion that the subjects may not have fully understood each question asked of them places further doubt on the accuracy and comprehensiveness of the answers. In light of these shortcomings, the effectiveness of the narrative in the other areas must also be held suspect: although the responses were generally reasonable and expected, it is quite possible that they were incomplete.

The narratives were knowingly collected in suboptimal conditions: time was short, translators were few, and confidence was minimal. With almost all interviews lasting less than thirty minutes, it is unexpected that subjects will move that quickly into more personal or sensitive topics or feelings. The ability to talk directly without an intermediary is impossible without knowledge of the language; alternately, a translator could have been trained more heavily in the methodology and intent of the interview, but this too was severely constrained by time and manpower. Building trusting relationships with subjects such that highly personal conversation is elicited is also impossible in this short time frame, while surrounded by a clinic treating dozens of other community members. When concern that one's care may be affected by the answers given is added as well, it is difficult to put great stock in many of the narratives gathered.

The implications of this are important and extend beyond the scope of this project. While medical anthropological studies may be done with great care and ample time, very few providers of medical care have this luxury, particularly those providing care in a setting such as rural sub-Saharan Africa. So few physicians practice in these patient populations that it is very unlikely that any one patient is receiving longitudinal care:

medical personnel are almost always meeting their patient for the first time, without the benefit of a previous relationship, and rarely have extended amounts of time to spend on each individual. The situation in the offices of American primary care physicians is not so different: faced with pressures to see as many patients in as little time as possible, the interaction between doctor and patient is often more business-like than personal. This is compounded by Western medical training that has largely focused on biomedical processes rather than what the patient is thinking and feeling. Proponents of the medical narrative posit that it should be a part of the physician's every day practice. However, this study demonstrates that, if medical narratives are not elicited under the proper conditions, they may give no insight into a patient's explanatory model, invisible barriers, lived experience of illness, or effect on the immediate or larger community. In fact, they may even give an incorrect view. This could be quite dangerous: if a practitioner seeks a patient's medical narrative, receives an inaccurate story, and acts upon the information with faith in its accuracy and completeness, treatment and interaction with that patient could be entirely misguided. As Bury writes, it is tempting but reckless to simply "treat patient narratives... as if they represented a form of unalloyed subjective truth, the authentic voice of the patient 'underdog' as opposed to the voice of dominant medicine or that produced by more quantitative survey data".⁶⁸ Each medical narrative obtained must require careful thought and interpretation within the context of the patient, interviewer, environment, and culture in order to glean from it information that can safely be acted upon.

This is not to suggest that the medical narrative is useless. On the contrary, it has proved its worth countless times in numerous contexts. However, when not conducted in

the correct conditions, this study suggests that the medical narrative may not be a true or complete reflection of that patient's illness experience. It is important that practitioners who attempt to employ this methodology understand these limitations. Further research into the methodology of the medical narrative is also recommended; for the medical narrative to be truly useful, we need to know what conditions affect medical narrative response and which of these are most important. We must also know how best to adapt the carefully constructed medical narrative of the "lab" to the constraints of the physician practicing in the field.

Recommendations for Unite For Sight partner clinics

Providing adequate health care in general and eye care in particular to the people of Ghana continues to present many challenges. It is primarily financial need that stands in the way. Issues such as a shortage of physicians, particularly in rural areas, and the need for the rural poor to travel long distances in order to receive for health care beyond traditional healing also remain barriers.

Unite For Sight and its associated clinics have developed a good model for delivering care to the rural poor of Ghana. Examinations and surgeries are provided free of charge, and glasses and medication are distributed at relatively nominal fees; this significantly lessens financial barriers. By bringing eye care to the villages themselves through mobile clinics, the barrier of distance, transportation, and lack of medical personnel is eliminated. Another positive aspect is the close way in which the clinics work with the local communities and leadership; by going through the chief or other

village leaders, the clinics are able to reach and to gain the trust of more patients more quickly.

There is, however, room for improvement. One important component of the Unite For Sight model is patient education and counseling. The patients as a group should be educated in steps they can take to prevent eye disease and injury. Misinformation, such as that all blindness is an irreversible consequence of aging, can also be dispelled. By providing the group with information ahead of time, discussion with family and fellow village members can take place before consultation with the doctor. This may allow patients to feel more comfortable discussing what might otherwise feel like foreign ideas and treatments.

One of the clinics was very intentional about beginning each outreach with a educational session for the villagers in attendance, discussing what they could expect to happen that day, various common eye diseases, good eye health practices, and how surgery would happen if they were referred; each session concluded with a period of time in which the people could ask questions. The same clinic did a good job of counseling patients more intensively one-on-one whenever necessary. The patients of this clinic largely had accurate explanations of their eye condition, even if they didn't use the Western medical terminology: for example, one woman with cataracts used what became a common metaphor for cataract, "stones" in her eyes. This same woman had a very positive outlook for her upcoming surgery; when asked if she thought the surgery would help, the woman replied, "they said it, so I believe it. I heard from people that were operated, and they can see, so I believe it".

The other clinic was far from ineffective, and provided quality care to many patients; however, a comparison between the two elicits interesting observations. This clinic put a much smaller emphasis on education and individual counseling, focusing instead on just conducting examinations and providing care. Although a significant number of the subjects treated by this clinic had a good understanding of what their condition was, a substantial number were very confused or vague regarding what they had been told by the clinic staff. For example, one woman did not remember until prompted by a member of the clinic staff that she had cataracts, and did not know what the eye drops that had been given to her were for. Also, a higher number of those referred for (free) cataract surgery refused in comparison to the first clinic. Perhaps if more time were invested in explaining the realities of the surgery to the patients and counseling them as to the benefits and possible risks, more individuals would have taken advantage of this gift.

The biggest difficulty in implementing such education is that it requires time and staffing, two things that are almost always in short supply when conducting an outreach clinic. However, if patients do not understand their diagnosis, they may not understand that it can be treated or stopped from progressing; if they are not educated on how to use their eye drops correctly, they may not get enough medication or may even use too much, causing further eye damage; if their experience with the clinic is not a positive one, the stories and anecdotes they provide to people in their families and communities may prevent others from trusting and seeking out medical care from a biomedical source in the future. Part of the allure of traditional healing is the personal nature of the interaction; the more robotic and impersonal that practitioners of Western scientific medicine in rural

Ghana seem, the less effective they and any future care providers will be. There are important lessons to take from the traditional healer: it is helpful to know the community well or work through a contact who does; resist the brusque nature of scientific medicine as it is viewed by the patients and provide mental and emotional support along with the physical; and focus not just on treating illness, but preventing it as well. Rather than condemning all aspects of traditional healing, perhaps it would be useful for clinics to form relationships with healers and to work together to provide a truly comprehensive form of care to patients.

Conflicts of Interest

The author served as a Unite For Sight Global Impact Fellow in Chennai, India during Summer 2008 and while this study was conducted during Summer 2009. She also has served as the Carnegie Mellon Unite For Sight Campus Representative (Fall 2008 through Spring 2010).

Acknowledgements

This project was supported and advised by Dr. Marie Norman, Carnegie Mellon University Adjunct Professor of Anthropology in the Department of History. Her guidance in the development of this thesis has been critical. The project was funded by a International Small Undergraduate Research Grant. These results and conclusions represent the views of the author and not those of Carnegie Mellon University.

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