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WHAT'S TO KNOW?: NAVIGATING KNOWLEDGE GAPS OF HANSEN'S DISEASE IN THE U.S.

by

KRISTEN ELISE KUHNS

Under the Direction of Cassandra White

ABSTRACT

This thesis uses a critical medical anthropology approach to explore healthcare professionals' perspectives of Hansen's disease (HD) patients' treatment-seeking experiences in the United States. During semi-structured interviews my eight informants discussed challenges patients face when seeking treatment. The number one challenge discussed was that of knowledge gaps among healthcare professionals which influence misconceptions of HD being highly contagious and dangerous. Such misconceptions negatively influence patients' treatment from start to finish. My informants discussed their understandings of, and roles in minimizing challenges for their patients.

INDEX WORDS: Hansen's disease, Knowledge, Healthcare professionals, Treatment-seeking, Healthscape, Stigma, Critical medical anthropology

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by

KRISTEN ELISE KUHNS

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2012

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2012

WHAT'S TO KNOW?: NAVIGATING KNOWLEDGE GAPS OF HANSEN'S DISEASE IN THE U.S.

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KRISTEN ELISE KUHNS

Committee Chair: Cassandra White

Committee: Bethany Turner

Scott Catey

Electronic Version Approved:

Office of Graduate Studies

College of Arts and Sciences

Georgia State University

May 2012

DEDICATION

This thesis is dedicated to all the patients my informants' clinics treat and cure. May your road to recovery be blessed and may the physicians and nurses desire to help never go unnoticed.

ACKNOWLEDGEMENTS

I would like to acknowledge my advisor Dr. Cassandra White who has dedicated her own research to understanding the experiences of immigrant HD patients. Dr. White's efforts, guidance and support have been invaluable not just to me, but all those she has worked with. I would also like to acknowledge the healthcare professionals who offered me their time and shared their experiences. Without your insights my thesis would not have been possible. Additionally, the guidance of my committee members Dr. Bethany Turner and Dr. Scott Catey were crucial in helping me to develop my thesis into the best product possible. Thank you for challenging me to do my best and more. Finally, my family and friends have been my number one advocates in the past six years of my schooling and gave me the constant support I needed to make this possible. Thank you all! Your support, kindness and guidance have not gone unnoticed and will never be forgotten.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS v

1 HANSEN'S DISEASE: WHAT'S TO KNOW? 1

2 METHODOLOGY 26

3 SEEKING TREAMENT: GETTING TO THE CLINIC IS HALF THE PROBLEM….. 38

4 SEEKING TREAMENT: ….BUT WHEN THEY FINALLY GET TO THE CLINIC 51

5 A CLASSIC CASE OF CATCH 22 66

6 BREAKING FREE OF THE CATCH-22 PARADOX 73

7 REFERENCES 80

8 APPENDICES 102

Appendix A 102

1 HANSEN'S DISEASE: WHAT'S TO KNOW?

> "The late nineteenth-century Western opinion that leprosy was highly contagious…was not formed through extended observation and careful studies of the behavior of the disease. Rather, it was formed by the general attitudes held in Western nations about the character and the symbolic attributes supposedly possessed by the colonial populations in which the disease was presumed to be inherent" (Gussow 1989:20).

Hansen's disease (HD), more commonly known as leprosy, has historically been viewed as an immigrant disease in the United States (U.S.) by policy-makers as well as portrayed as such by the popular media (Gussow 1989; Moran 2007). This view is despite the fact that HD has never been eradicated in the U.S. and the fact that 20% of current cases are endemic. However, as discovered during this study, challenges patients face are due more to the characteristics of the disease (e.g., stigma or misconceptions) than the identity of the patient (e.g., immigrant or citizen).

Hansen's is a disease of many misconceptions. Common misconceptions include that HD is highly contagious, that the disease may cause peripheral limbs to rot off, and that having HD is a sign of an impure soul or punishment (Gussow and Tracy 1968; Lewis 1987; Volinn 1989; White 2010). Many misconceptions of HD in the Western world are based on Judeo-Christian understandings of the disease present in ancient religious texts. In recent history, these understandings have been alternatively challenged and reinforced as Western biomedical practitioners learned more about the disease process and as varied cultural perceptions of the disease have shifted with increasing exposure to different cultures understandings of the disease.

Exposure to these shifting perspectives about HD has not resulted in an acceptance of those affected in the U.S., or elsewhere. These perspectives have been developing and shifting

since the late 19th century when more people began to migrate to the U.S. and subsequently brought more cases of HD into the country (Moran 2007). Policy makers reacted to the increasing number of people migrating to the U.S. from endemic areas resulted in enforcement of isolation policies at institutions, or leprosaria, on the colony of Hawaii and in the state of Louisiana. While such isolation policies were abolished in the U.S. in 1960, many of those patients continued to live at the hospitals at those facilities until the late 1990s (Microbiologist Informant 2012). Many of the immigrants patients originally settled in port cities. However, new movement of immigrants into non-port cities in the mid-20th century resulted in the National Hansen's Disease Program (NHDP) having to expand their focus beyond ambulatory clinics that had been originally established at former merchant marine hospitals in coastal areas (Microbiologist Informant 2012). This also resulted in new challenges as the NHDP worked to advocate for patients in these new locations by spreading awareness of the disease and establishing new clinics.

One explanation for these new challenges was offered by a HD research informant who said that the knowledge about the disease, whether that knowledge is biomedical or patient-based, was restricted to people at the original HD ambulatory clinics. This, coupled with the fact that medical training in the U.S. spends less time on diseases that are not a serious health concern in the U.S. (Physician Informant 2012), has resulted in a gap in biomedical knowledge that has negative outcomes for patients. In this scenario, knowledge gaps emerge in the discourse that influence HD patient treatment-seeking experiences. One type of knowledge gap is when healthcare professionals just do not know what the disease looks like, especially in its early stages, and subsequently do not know how to diagnose the disease. This results in a delay in

diagnosis which can lead to serious manifestations of the disease for the patients. Another type of knowledge gap is the misunderstandings of the disease, often based on popular conceptions of Hansen's. This results when healthcare professionals know what HD is, but believe the disease is highly contagious and dangerous leading to patients either being denied care or being treated as objects that should be carefully handled. Knowledge, either lack of or misinformed, and the process that creates that knowledge becomes a system creating confrontation between patients and healthcare professionals and patients within the healthcare system.

As 80% of HD cases in the U.S. are among immigrants, who likely acquire the disease in their country-of-origin, an additional discussion is warranted here (Carus et al. 2011, WHO 2011). Healthcare resources for non-citizens in the U.S. have increasingly been limited and even become non-existent. Such limitations are directly linked to poorer health outcomes, primarily because costs govern decisions to seek treatment (Derose et al. 2007; Chernew et al. 2005). Barriers to treatment-seeking extend beyond financial concerns. Many immigrants worry about being able to access adequate care and are concerned about how they may be treated. The original intent in the design of this thesis was determining what types of challenges healthcare professionals recognize their immigrant HD patients experience as well as how their facilities work to eliminate such challenges. However, as interviews progressed it became clear that while being an immigrant with HD could result in double stigma that is negatively experienced by patients, the issues for HD patients had more to do with knowledge gaps discussed in the last paragraph. Therefore, this thesis is an attempt to unravel how knowledge of the disease among healthcare professionals both enables and disables patients' treatment-seeking. Addi-

tionally, I hope this thesis contributes to the larger literature in medical anthropology of positive examples of patient-healthcare professional interactions.

While I draw on various theoretical frameworks, the thesis is primarily informed by critical medical anthropology (CMA). Such an approach allowed me to evaluate the multiple factors influencing treatment seeking at a global, national and community level of analysis (Singer 1995). However, I was careful in my research design because this project involves a studying-up approach (Nader 1972). I wanted to capture healthcare professionals' accounts as healers, not "externalist academic accounts" focused on the "influences of social forces" (Kleinman 1988:210) that studying-up may produce. I also found my work informed by Arjun Appadurai's (1991) notion of the ethnoscape; I draw on his concept of global landscapes and use the term "healthscape" to make it specific to immigrant experiences of the U.S. healthcare system. Appadurai (1991) encourages anthropologists to renegotiate ideas of local ethnography in a complicated transnational globalizing world. Therefore, I conclude the thesis by discussing the the boundaries of national, global and local knowledge as I work to situate such knowledge at a level of analysis that is individually relevant to patients and healthcare professionals.

What is Hansen's disease?

HD is a curable chronic bacterial infectious disease that primarily affects the peripheral nerves and mucous membranes. The etiological agent of the disease is the acid-fast bacillus *Mycobacterium leprae*. The bacillus was discovered by Gerhard Armauer Hansen in Norway in 1873. (Gussow 1989). HD was named after Hansen decades later through an attempt to reduce stigma induced when the disease was referred to as leprosy. This push to rename the disease

was led by patients at the leprosarium in Carville, Louisiana (Stein 1963). According to the NHDP symptoms of HD include skin lesions that are discolored skin or anesthetic patches (NHDP Frequently Asked Questions 2012). There is no other skin condition that causes loss of nerve sensitivity (Microbiologist Informant 2012). However, for a definitive diagnosis, a skin biopsy must be performed.

There are two classifications of HD: paucibacillary (pauci-) and multibacillary (multi-). According to the U.S. Centers for Disease Control (CDC) pauci- HD is a less severe form where patients typically suffer from skin macules that are hypopigmented (CDC 2009). Multi- HD is characterized by complications with the nasal mucosa, skin lesions, thickened dermis, and skin nodules (CDC 2009). Severe nerve damage, caused by delay in diagnosis and treatment, can often lead to secondary infection. Delay in diagnosis can also result in severe manifestations of the disease characterized by acute immunological complication and acute lesion inflammation (NHDP Frequently Asked Question 2012). Despite these advanced complications, localized nerve damage is not known to lead to impaired cellular immune response or wound healing (Siddiqui at el. 2002; Pathologist Informant 2012).

HD is transmissible but not highly contagious. As a HD research informant put it, you might have to try to get it. Additionally, 90-95% of the world's population is believed to be genetically immune to HD (American Leprosy Mission 2011). However, as many informants state, we cannot be so certain. Transmission can occur through exposure to droplets in the respiratory tract where the bacterium thrives in cooler conditions of the nasal passages. The CDC (2009) identified risk groups as those with close contact with untreated patients, often prolonged contact, as well as those living in endemic areas. Lockwood (2004) identified these endemic areas

as India, Brazil, Nepal, Myanmar, Mozambique and Madagascar where 85% of worldwide cases are located. Other countries from which my informants' patients came from included the Marshall Islands, Mexico, Pakistan, countries in sub-Saharan Africa and the U.S. According to the World Health Organization (WHO 2012) in 2011 the global prevalence of HD was 192,246 cases across 130 countries and territories.

Additional risk factors include crowding and living conditions (Kerr-Pontes et al. 2004). Risk factors can also be culturally and geographically specific. In a study by Kerr-Pontes et al. (2004) in Brazil, it was found that inequality produced from rapid population growth, which causes overcrowding, and the proximity of the railroad, a source for the rapid movement of people, was associated with higher prevalence of the disease (cited in Lockwood 2004). Diana Lockwood (2004) suggests studies investigating the links between poverty and crowding as underlying risk-factors for transmission (Kerr-Pontes et al. 2004) are groundbreaking because they recognize HD as a disease of inequality that may manifest more rapidly in poverty-like settings.

With treatment HD can be cured by inactivation of the bacteria. According to the NHDP treatment "rapidly renders the disease non-communicable by killing nearly all the bacilli within a few days" (NHDP Frequently Asked Questions 2012). Treatment involves a multi-drug therapy. This therapy includes antibiotics such as Dapsone, Rifampin and Clofazimine and other sulfone drugs. Use differs depending on the type (pauci- or multi-) and patient conditions. As many of my informants noted in my interviews, each case is different. The NHDP (Frequently Asked Questions 2012) suggests two years of treatment for multi- HD and one year for pauci-. This is in contrast to the World Health Organization (WHO) which suggests one year for multi- and six months for pauci- (Microbiologist Informant 2012; Pathologist Informant 2012). The side effects

can often be disturbing. Rifampin can cause a patient to pee red, clofazimine can cause skin discoloration, and thalidomide (sometimes prescribed for leprosy reaction, described below) can cause serious birth defects. Treatment may not be successful if it is shortened or occasionally discontinued.

Another complicated aspect of the experience of HD is something known as “leprosy reaction” - which approximately half of patients experience (Jacob et al. 2008). The NHDP identifies reactions as a response to “dead or dying bacteria” which can affect “sensation and/or [sic] strength” (NHDP Frequently Asked Questions 2012). Reactions can result in new lesions, worsening lesions or inflammation and pain by promoting nerve damage (Jacob et al. 2008). There are three types of reactions. The rarest type, the third type, is called Lucio and most likely is found among patients with “long-standing, advanced leprosy” where patients may “develop a complication in which blood vessels that supply blood to the skin become occluded and they [patients] have a necrosis of large areas of skin” (Pathologist Informant 2012). The first type, and most common, is called a reversal reaction and is likely due to what my informant called an “upgrading of the patient’s immune response” (Pathologist Informant 2012). This reaction is treated with the anti-inflammatory prednisone. Prolonged use of prednisone can actually suppress the body’s ability to produce its own steroids which can be an additional medical complication (Pathologist Informant 2012). Erythema nodosum leprosum (ENL) is the second type of reaction of which even less is known. My informant did state that it appears to be an acute, non-chronic, inflammatory response. This type of reaction also responds to prednisone. Thalidomide may also be used to treat both type one and type two reactions (Pathologist Informant 2012). If not treated with anti-inflammatory drugs, such reactions could cause further damage

to the nerves (Jacob et al. 2008). Given the complications that can arise during treatment, as well as the length of treatment, success requires ready access to treatment.

As it may be clear, very little is definitively known about HD and the reactions. With patients wanting definitive answers, the case-by-case treatment of HD does tend to cause frustrations among patients. The lack of definitive answers also makes communicating about the disease difficult. These things considered treatment of HD is difficult for both healthcare professionals and patients making spreading awareness about disease treatment imperative for all those involved.

Motivations

I decided to go into anthropology because it was a field where I could study different cultural systems of health from the viewpoint of patients. Throughout high school I had been interested in how stigma affected how society reacted to patients of infectious disease. These reactions were typically driven by fear of something whether it is due to misunderstanding of contagion or complete ignorance. While I was interested in society as a whole, I was more interested in how those perceptions affect patients. I had planned on doing my undergraduate Honor's thesis on stigma of STD's among college students and how such perceptions influence treatment-seeking decisions. However, the year I wrote my thesis was 2009-2010, when the H1N1 outbreaks had the world in a panic and therefore I refocused my topic. My thesis became more about the fear and if that motivated students on the University of Maine campus to seek treatment. While I did not have a focus on stigma, I was still able to document how the University of Maine emergency response policies influenced students' decisions to seek treatment.

Going to graduate school in a big city resulted in me being more exposed to how treatment-seeking is differentially experienced among heterogeneous groups of people. The University of Maine campus was a great place to conduct research, but 80% of the student body was white/non-Hispanic and mostly U.S.-born citizens (College Board 2010). During graduate school I began volunteering with various organizations that provide support services for immigrants and refugees. Within my interactions with these organizations, and the people they serve, I began to see how treatment-seeking can be severely complicated for groups without access to numerous resources like my former informants, college students. I began to understand health disparities and how they influence not only treatment-seeking but also overall health of many immigrants and refugees.

A major focus of the questions for my informants focused on what barriers healthcare professionals noticed immigrants encounter when seeking-treatment and what problems these barriers presented for them as healthcare professionals. Some of the barriers identified included language, transportation, financial concerns and trust. It was clear in my interviews how dedicated these healthcare professionals were to their patients. The first clinic I gained access to recently received funding from the NHDP and was seeking help in implementation of their program. I was intrigued by the hyper-awareness the healthcare professionals had of the considerations that had to go into such implementation. Healthcare professionals at every clinic (four clinics total) discussed such considerations so this was not unique to this one clinic.

Informants from each clinic recognized they could not just publically advertise their status of being HD clinics because of misconceptions of the disease. Community outreach to spread the awareness of their clinic and resources for HD patients had to be strategically

planned. While each healthcare professional recognized that many immigrants would be more likely to experience health disparities, each recognized the stigma surrounding the disease was more important to consider. I pondered how such tip-toeing could be yet another challenge to treatment-seeking.

Immigrants

Within the U.S. recent ideas of HD in media and popular discourse often reflect nativist sentiments and include conceptions of HD as a highly stigmatized disease. HD has never been a serious public health concern in the U.S. Since reporting of HD prevalence began in 1824, the number of new cases reported yearly has never exceeded 500 (NHDP 2012; White 2010). Approximately 80% of HD cases in the U.S. have been reported among immigrants who acquire the disease in their country of origin (Carus et al. 2011; WHO 2011). However, it is a common misconception is that HD is strictly an immigrant disease. Between 10-25% of yearly reported cases are among U.S.-born citizens. At one clinic healthcare professionals treat primarily U.S.-born citizens. Knowing this, it would be wrong to call HD an immigrant disease.

In 2005, Lou Dobbs, on the CNN program *Lou Dobbs Tonight*, discussed the disease as originating from 'illegal aliens' who were bringing the disease into the U.S. On the show, Dr. Madeline Cosman, a lawyer and medical historian, was quoted as writing that there had been 7000 cases in the past three years in the U.S. The NHDP (2012) registry reports only 500 new cases total between 2002-2005. These yearly reported numbers do not discriminate between immigrant and native cases. This broadcast, as well as others, become a "technique of power" (Foucault 1990:141) whereby viewers are fed a supposed truth that immigrants bring disease

threatening the imagined community of the Nation State (Anderson 1983). The media becomes a vector for creation of false truths (Appadurai 1991).

In 2008 the public of Springdale, Arkansas found out that among their population of 60,000, nine cases of HD existed among the Marshallese population. The story breached state lines and hit national news broadcasts. One local doctor went as far as to say in a news interview with KFSM-TV that the problem was immigrants from the Marshall Islands not complying with treatment protocol. The news broadcast suggested that if such compliance was not practiced, an epidemic was looming, because of the immigrants. Such depictions encourage nativisit sentiments despite their absurdity. Many viewers of this show may not know that as part of a treaty between the Marshall Islands and the U.S. military, as a result of nuclear testing in the 1950s, Marshallese are allowed to enter into the U.S. with only a passport; no visa required (Pathologist Informant 2012). The CNN and Arkansas examples are only two of many examples of the misconceptions of the link between HD and immigrants. Some argue that HD has become the fuel for nativist sentiments. These sentiments are not the only challenges patients, if immigrants, may face.

Health services in the U.S. are expensive and increasing costs govern coverage by health insurance plans, both public and private. As Rose Weitz (2012:193) says, “the most basic element in any nation’s healthcare system is how it provides and pays.” Decreasing, limiting and non-existent coverage has been directly linked to poorer health outcomes, primarily because costs govern decisions to seek treatment (Derose et al. 2007; Chernew et al. 2005). The barriers created by the shifting costs for health insurance have greatly affected the poor in the U.S. who are already an at-risk group for decreased quality of health. Since many immigrants enter the

U.S. workforce in the lower-end of the job market, they are made increasingly vulnerable to socioeconomic barriers (Chavez 2003). Non-citizen immigrants, and U.S. citizens alike, who live at or around the poverty line typically only qualify for managed care plans. These plans are coming under increasing pressure at the National and State level with budget cuts (Greene et al. 2005). Limiting access that immigrants have to such services has increasingly become the solution to decrease expenditures. Such limitations will be discussed more thoroughly in the next section. One explanation offered by Meredith King (2007:1), from the Center for American Progress, is what she calls the "myths that misinform the American public." Such myths include that immigrants overburden an already limited supply of healthcare resources. This myth exists despite the fact that 33.2% of documented immigrants in the U.S. do not have health insurance and practically all undocumented individuals are uninsured (Castañeda 2010; Jenks 2007).

Many immigrants are vulnerable due to an "increased risk for poor physical, psychological, and social health outcomes and inadequate health care" (Derose et al. 2007:1258). Immigrant populations are heterogeneous making increasing services to them more difficult to negotiate as their needs vary (Derose et al. 2007). Today in the U.S., the majority of immigrants are likely to come from non-industrialized countries, such as in Asia and Latin America, where poverty contributes to the increased likelihood of being exposed to infectious and parasitic diseases that are endemic and where access to care may or may not have been more limited (Loutan 2001). In conversations with Dr. Cassandra White (2012), who conducted anthropological research on HD in Brazil, she said, "HD treatment is readily accessible at health posts whereas in the U.S. there are only a small number of ambulatory clinics where you can get treatment." Every healthcare professional I interviewed recognized such differences. While each in-

formant had specific examples of such cultural differences, they recognized the challenges for many immigrants are universally felt. The healthcare professionals, however, were more concerned about the stigma of HD.

Stigma

HD is not universally stigmatized. In some societies, HD stigma has resulted in ostracism where individuals are cast out from their society. HD was discussed as a sign of moral transgression in both Judeo-Christian and Hindu religious texts, for example. However, in some cultures, people affected by this disease suffered no social ostracism. Since stigma did not exist in parts of sub-Saharan Africa before European colonialism, Vaughan (1991) suggests that stigma resulting in ostracism was introduced by missionaries who used stigma in an effort to convert more people. Similarly, in New Guinea, where HD prevalence is high, it is not seen as a serious disease (Lewis 1993). Gilbert Lewis (1993:203) stated that the villagers in New Guinea had a general "disbelief that the people diagnosed with leprosy really have a serious disease."

Where stigma does exist, it acts as a "deeply discrediting" force (Goffman 1963:3) where it is internalized as contributing to an inferior quality of self (Kleinman 1988). Stigma can cause a crippling affect that "create problems in the presentation of self" (Kleinman 1988:159). Whether the stigma is stamped onto the individual as with examples Arthur Kleinman (1988) uses such as the yellow Star of David, the scarlet letter or dunce cap, or manifested onto the self through advancement of the disease such as with HD lesions, or physical disfigurement, the visibility of the disease, symbolic and physical, is key in understanding how society reacts to victims of stigma.

Society reacts against those with a discrediting condition because such a condition is in stark contrast to typical cultural conventions and categories and thus might fall into categories "of what is ugly, feared, alien or inhuman" (Kleinman 1988:159) and subsequently result in a taboo. Breaching typical conventions and categories could likely result in both physical and symbolic isolation, especially if the taboos have moral connotations (Kleinman 1988; Douglas 1966). Stigma of HD is often associated with the external manifestations of the disease on the skin. The categorization of an individual having 'leprosy' has historically been attached to those with any skin condition (Zias 1991). In 1984 a mass grave was discovered near the Jordan River at a monastery with the remains of 400 individuals (Zias 1991). Many of these individuals were believed to have had HD. However, the investigative team was able to determine most of the individuals suffered from other chronic diseases (Zias 1991), many of which likely had skin conditions that were not HD. In ancient times, the stigma of HD reflected religious connotations of sin and impurity causing such a condition to been seen as a punishment from God. The story of Jesus healing "lepers" conveys this as only God could reverse such a punishment and by affect make the soul pure again. Douglas (1966) would argue that such ideas of contagion and punishment are a reflection of how society organizes systems of understanding of what is normal and what is not.

Stigma is not only externally discrediting but also internally projected. Internalized stigma associated with fear of discovery of a patient's condition can have a negative effect on treatment-seeking (Shaikh et al. 2007). Such fears can be seen in the experiences of undocumented patients. Undocumented individuals risk discovery, and subsequently deportation, if they access healthcare services. One such immigrant group that may often experience this is

undocumented working class Mexican immigrants. This group has been subjected to stereotypes of being unhygienic, as Horton and Baker (2009) documented in a study of Mexican immigrant children with oral hygiene problems. Mexican migrant children in California's Central Valley often had oral hygiene problems and were seen as dirty by other community members. Furthermore, their mothers were subjected to classifications of being bad mothers who did not care about their children's health. However, mothers did not access healthcare services for their children for fear of discovery of their undocumented status. Our society, as Nancy Scheper-Hughes and Margaret Lock (1987:25) suggest, is a health-focused culture governed by an individual's decision to "live right, to eat well, to exercise, etc." In this example, the undocumented immigrants were subjected to U.S. perceptions of hygiene, as reflected in the aesthetic image of the teeth. Bad teeth were viewed as dirty and reflecting negligence. Uncleanliness became "matter out of place" which is approached "though order" (Douglas 1966:50) by classifying the mothers as unfit. The body is a cultural artifact that symbolizes health and therefore purity (Douglas 1966; Scheper-Hughes and Lock 1987).

Some immigrant groups are often portrayed, particularly by those with an anti-immigration agenda, as bringing disease. This is especially the case with more stigmatizing diseases such as HIV/AIDS, tuberculosis and HD. Contemporary examples include "linking AIDS to Haitian immigrants, mental pathologies to Cuban immigrants, and malaria to Mexican immigrants" (Chavez 2003:207). In the early days of the AIDS epidemic, simply being Haitian was perceived as an increased risk to having HIV/AIDS. The association of nationalities with HIV/AIDS by the Centers for Disease Control contributed to an increasing xenophobic society (Volinn 1989). These associations of disease with groups of people have left such groups to

what Chavez (2003:208) terms “pariah status” of some immigrants groups with that of a “leper,” ironically demonstrating the continued metaphorical power of this term (Volinn 1989).

Stigma goes both ways. Not only does the host country have perceptions of disease but so too does the sending country. These perceptions often conflict or enforce the experience of stigma. Patients who suffer from some of the most stigmatizing conditions, such as HD, are typically subjected to enacted stigma whereby an individual is seen as possessing a discrediting syndrome making the individual morally, socially and physically stained (Goffman 1963; Lichenstein et al. 2005). The stigma of uncleanliness also acts as a means to prevent patients from accessing healthcare. The fear of discovery of disease status is evident in the experience of patients in India with HD. In India, HD is highly stigmatized and even confers what Goffman (1963) refers to as courtesy stigma whereby “friends and relatives of people with HD risk severe social and economic losses for their affiliations” (Barrett 2008:105). In India HD patients will travel to communities elsewhere to seek treatment in order to avoid disclosure of their disease status (Barrett 2008). Patients in India often seek out Ashrams in order to not only be treated but to be washed of their impurities, a symbolic rite that must occur for the individual to be successfully treated. The Aghori, studied by Ron Barrett (2008), create a comfortable environment and by association with such pure individuals, HD patients hope to become pure once again. This is despite that Aghori themselves have traditionally being highly stigmatized. However, through their service with people affected by HD, they have come to be seen in a more positive light, even though HD is still stigmatized in India. In contrast to this self-stigmatization, HD patients from other countries, like Brazil, where there has been a concerted effort by the

Ministry of Health and NGOs to destigmatize the disease over the past few decades, may not self-stigmatize in the same way.

Facilities for treatment may not be available in host countries, making culturally relevant healing and treatment procedures that stand for symbolic ritual washing of impurities, as attained as Ashrams, difficult to acquire in a Western biomedical system of healing. In other parts of the world facilities for HD patients, leprosaria, have historically served other purposes, namely complete isolation of those affected by the disease to ease public fears of transmission (Fairchild 2006). Isolation, or exclusion, beyond the context of HD patients, can also be attributed to the fear of otherness. As Michel Foucault (1970:xxiv *in* Chavez 2008) states on otherness, "for a given culture, at once inferior and foreign, therefore to be excluded (so) as to exorcise their interior danger" the "mythic qualities" (Chavez 2008:22) of undocumented immigrants push them into the category of other where they are isolated. While Chavez (2008:22) uses this phrase in the context of the "mythic qualities" of the undocumented other, these qualities are also discussed at length in King's (2007) report on immigrant experiences accessing healthcare services in the U.S.

In terms of HD, exclusion is mostly due to historically rooted perceptions of HD being a debilitating disease that is highly contagious and notions of uncleanliness. These perceptions have contributed to isolation policies. White (2009) notes that fears of HD in Brazil used to be associated with the leprosarium era in which patients were secluded. However, patients in Brazil are now more often treated on an outpatient basis. This is despite the fact that some of the facilities in Brazil still have HD patients living on their grounds. Similar policies were implemented in the U.S. 1917 law requiring the isolation of patients to facilities such as those in Carville,

Louisiana and Hawaii (White 2010). Japan also enforced an isolation policy between 1909-1996 (Nashida et al. 2006). Additionally, immigrants entering the U.S. from 1971-1988 were screened for HD. If infected, such a status was a cause for denial for entry (Mastro et al. 1992). The fear among contemporary populations is rooted in the knowledge of a country's history of isolation and, as some of my informants noted, such fears affect treatment-seeking experiences.

Recent History

In the U.S. historical patterns and economic structures have been influenced by policy that has been built on exclusion of global cultural flows. As mentioned earlier, not all immigrant groups experience exclusion in host societies, depending on class, racial identity, education, linguistic ability, etc. and even these experiences differ. Contemporary interactions of such exclusion for HD patients, whether they be symbolic or physical, have evolved out of imperialistic public health policies in the U.S. (Moran 2007) that are in-sync with notions of the "nation-state project to align social habits, culture, attachment, and political participation" (Ong 1999:2). Colonialism opened up a new pattern of migration across the globe. When the colonized began to move as the colonists did, such movements increased exposures and subsequently threatened the nation-state (Gussow 1989). Immigration policy and HD policy became linked and reflected prejudicial, racist, and xenophobic attitudes.

In the early 20th century a large number of Chinese immigrants were migrating to the U.S. in search of new opportunities. The USG reacted by establishing of The Chinese Exclusion Act of May 6, 1882 (Lee 2004). This was the first piece of legislation to purposefully exclude immigrants from the U.S. Establishing the Act served the purpose to exclude Asian immigrants

perceived to be infiltrating the western coast of the U.S. (Lee 2004; Moran 2007). This reaction was also a way to protect the purity of the Western way of life from outside dangers. The Act was also established during a transitional state where Germ Theory was emerging. Zachary Gussow (1989:112) wrote that whereas all the epidemics in world history had been widely observed as "cutaneous condition[s]" diseases, with Germ Theory, they became "distinguishable clinical entities." However, during this transitional state, HD was the only disease that Western-nations claimed no ownership of and instead was ascribed to "inferior peoples" who "could bestow on the civilized west" (Gussow 1989:112). This recognition, as well as an awareness of an ongoing HD epidemic in Hawaii among its Asian occupants, contributed to what came be known as the yellow peril (Lee 2004; Gussow 1989; Moran 2007).

During this time there was a general fear the HD would spread to Western Nations. This is despite the fact that is was present in Norway and had been present in the U.S. However, in Norway the disease was controlled by scientific advancements and through humane public health interventions (Gussow 1989). Despite such advancements, the epidemic in Hawaii motivated the establishment of policies of isolation as attitudes and fears of a pandemic became the mechanisms of power relations. These power relations resulted in the institutionalization of those inflicted. The control of the Hawaiian colony at Kalaupapa on the island of Molokai became a metaphor for how domestic policies could mold national identity (Moran 2007). On the island, U.S. medical authorities managed treatment regimens through attempts to "police the sexual lives of patients, limit childbearing, intervene in child rearing, and regulate the creation and maintenance of domestic spaces" (Moran 2007:6). Through such management, national

character was protected by ordering “separate areas of existence” (Douglas 1966:50) for immigrants.

In 1899 the U.S. Surgeon General attempted to calculate the prevalence of HD in the U.S. (Moran 2007). This survey was conducted by the Marine Hospital Services. These hospitals became part of the public hospital program which dates back to the time of John Adams (Microbiologist Informant 2012). After being closed by the Ronald Reagan administration in 1981, eleven of these hospitals became the first ambulatory clinics of the NHDP. The results of the Marine Hospital Services survey in 1902 conceded that the disease posed less of a threat then was thought. However, the medical officers conducting the survey still suggested establishment of two leprosaria to house HD patients (Moran 2007). With one already established on Molokai in Hawaii the next step was to establish one on the mainland to account for cases that were assumed to be present within the continental U.S. (Moran 2007). Many debates circulated among Congress about establishing a continental leprosaria. Moran (2007) suggests this was due to an inability to recognize the country could be vulnerable to what was assumed to be outside influences. Such vulnerability is responded to by establishing new boundaries through ordering and therefore those on the margins of such ordering, in this case those inflicted by HD, are bounded within institutional structures (Douglas 1966). Two decades later, in 1921, the USG bought the former Indian Camp Plantation in Carville, Louisiana which had come to be known as the Louisiana Leper Home. Patients diagnosed with HD were required to relocate to Carville until 1960 (Gaudet 1998).

The exclusion of Asian immigrants with The Chinese Exclusion Act of 1882 was “perfected” (Lee 2004:120) with the 1924 Immigration Act, which also “restricted the entry of southern

and eastern European immigrants through a national origins quota system" (Lee 2004:120). This policy was a reaction to the outcome World War I and the intent was to protect the nation's character as the perceived threat shifted from Asian immigrants to European immigrants. The nation's borders became a site for exclusion where vulnerable points were sheltered through exclusion and ordering during the vulnerable transition states the country experienced post-war (Scheper-Hughes and Lock 1987; Douglas 1966).

The Immigration Act of 1965 saw the abolition of this discriminatory system and instead was replaced by a system for "preference categories on family reunification and professional skills" (Lee 2004:120). This system set precedence for immigrants to offer specialized skills to contribute to the U.S. economy. The 1965 Act was one of the first steps the U.S. took towards acceptance of its immigrant origins in an attempt to align immigration policy with the Civil Rights Act of 1964. For a country built on immigrants, the heterogeneous identity of what Bourne (1916) termed the *trans-national America* was finally being embraced in an attempt to resist assimilation. The U.S. Department of Justice and Civil Rights Division has worked to eradicate discriminatory barriers through Title VI which states that "discrimination on the basis of race, color, and national origin, is prohibited" (Title VI of the Civil Rights Act of 1964). However, just because these mandates exist does not mean that inclusion is guaranteed.

Theoretical Implications

This thesis is informed by various theoretical frameworks that helped me to explain and contextualize my findings. Critical medical anthropology (CMA) is informed by an understanding that illness and health must be understood as being shaped by multiple macro and micro-level

forces (Singer 1995; Janes and Corbett 2010). CMA seeks to establish meaning in systems of social relations by investigating "real people doing real things" (Ortner 1984:144). However, CMA also paints a larger picture by investigating how micro-level social relations are influenced by the political economy, class structure, community level understandings of health, and global inequalities (Singer 1995). However, in order to give these forces a structure from which to operate I assigned the term healthscape; drawing on Appadurai's (1991) concept of global "scapes".

The healthcare professionals in this study recognized the challenges immigrant HD patients encounter when seeking-treatment in the U.S. These challenges are the result of dynamic interactions within the U.S. healthscape. The suffix *–scape* was used by anthropologist Arjun Appadurai (1996:33) to refer to "fluid, irregular shapes" of landscapes that are characterized by "global cultural flows." These landscapes, or as Appadurai (1991) called them "ethnoscapes", are what is resulting from new globalized communities that are no longer locally situated and subsequently deterritorialized. The cultural flows that result are influenced by the current state of the world in terms of multi-scalar economic, cultural and political conditions. Cultural flows can be further characterized as the deeply embedded personal perspectives of experience within a given *–scape* as "inflected by the historical, linguistic, and political situatedness" (Appadurai 1996:33). Disparities in access to health can be accounted for by "global cultural systems" that are "filled with ironies and resistances" (Appadurai 1996:29) and are determined by "historical settlement patterns and economic structure" (Hall et al. 2011:9). Within the healthscape treatment-seekers face a number of challenges and choices; CMA encourages researches to recognize how these challenges are complicated by local and global factors. In recognizing the-

se challenges, CMA questions why patient-healthcare professional relationships are the way they are and "analyzes the relationship not as an isolated dyad but as part of the medical system" (Lazarus 1988). The healthscape becomes the arena in which these conflicts battle for and against health justice.

As our world continues to globalize, the healthscapes within our world will continue to resist global cultural flows. This is evident in my work where the U.S medical training is slow to adapt to the ever-increasing globalization and deterritorialization of disease and illness. In this sense the healthscape can become violent to those who seek to navigate its structure. Structural violence is a term used to explain forces that prevent people from reaching their fullest potential (Galtung 1969). Furthermore, structural violence accounts for how society enforces the boundaries that "wreak[s] havoc on vulnerable groups of people" through exclusion (Bourgois and Schonberg 2009:16; Farmer 1999; Farmer 2004). Setha Low (2011) uses the concept of "spatialized culture" to address the inequalities created by such exclusions where certain structures limit or purposefully exclude entry into communities through symbolic policing and political-decision making. Such exclusion has consequences for patients, especially for some immigrants as the tensions between the territorialized nation is challenged by the deterritorialized global citizen (Ong 1999). The question becomes how to accommodate these non-citizens and their diverse understandings of heath and illness in the biomedical model of the Western world. Lewis (1993:215) discusses double standards of treatment where we are "cautious and critical of others, but not enough about ourselves." The restrictions and limitations are enforced in a dynamic synergy of policy and social relations that enforce subtle coercion (Foucault 1995) through control of access to critical health resources.

My work was also informed by Arthur Kleinman who has greatly contributed to medical anthropology literature on the relationships between patients and healthcare professionals. In using Kleinman's work I wanted to capture healthcare professional's accounts as healers, not an "externalist academic account" focused on "influences of social forces" that Kleinman (1988:210) himself has critiqued. My questions were designed to elicit narratives from healthcare professionals so as to uncover their own understanding of patient narratives. Medical anthropology has documented how such relations often fail due to the ignorance of sociocultural understandings of the etiology of disease and illness (Browner and Press 1996; Simon et al. 1996; Lewis 1993; Crandon-Malamud 1993; Scheper-Hughes 1992; Bellisari 1987). However, I will demonstrate in this thesis that this is not the case for many of the healthcare professionals I interviewed during this study. While healthcare professionals show an understanding and adaptation to the varied sociocultural understandings of the etiology of HD, the most critical challenge during patient treatment-seeking had to do with stigma of the disease and the incidence of knowledge gaps about the disease among healthcare professionals.

To explain such knowledge gaps, and how such a situation is contributed to by stigma, I pulled from Michel Foucault, Mary Douglas and Erving Goffman. In Foucault's work *Power as Knowledge* (2010), as well as various other works, I uncovered that power is not a terminal point but a system of processes and mechanisms that create institutions, law, and government which are the result of power and through which power is executed. In this explanation, Foucault's power produces "medical knowledges and medical experiences" (Lupton 2003:17) that are localized on the individual body. The knowledge I refer to throughout my thesis comes in two forms. One is the lack of knowledge that make diagnosis difficult. A delay in diagnosis re-

sults in advancement of disease as patients navigate deeper into the healthscape in search of an understanding healthcare professional. However, Foucault (2010) argues it is not about who has this knowledge and who does not; instead one must investigate why one person has and controls this knowledge that affects the patient while the other, the patient, does not. The second type of knowledge is where the knowledge of the disease is present but misconceptions greatly influence patient and healthcare professional interactions. Understanding of these knowledge gaps was made possible through a critical engagement with Mary Douglas (1966) and Erving Goffman (1963) who both investigate the categorization of people assumed inferior due to a discrediting condition which threatens personhood and subsequently society as a whole.

Summary of Chapters

In the next chapter I will delve into my methodology and explain the importance of my approach, specifically in the context of studying up. The third chapter will be an account of the macro-level forces healthcare professionals recognize as influencing the treatment-seeking experience of patients. The fourth chapter captures the micro-level forces healthcare professionals recognize as influencing the patient experience within the clinic and the interactions they have with their patients. My fifth chapter is an analysis of these challenges through an intertwining of the discourses the healthcare professionals used as well as an analysis of knowledge gaps. Finally, I end my thesis with a discussion of the implications of my findings and next steps.

2 METHODOLOGY

> "Predicting the points at which people will make decisions based on assessments of cost or likelihood of cure…is not the same as understanding how they do so" (Mathews 1982:177).

This study focused on understanding healthcare professionals' perspectives on difficulties immigrant patients with HD face when seeking treatment as well as personal challenges as healthcare providers to these patients. The primary methodology was in-depth, semi-structured, interviews with eight healthcare professionals at four clinics across the U.S. Three of these clinics were NHDP ambulatory clinics. I also interviewed a healthcare professional at a non-NHDP program clinic that treats many immigrant HD patients. My informants had varied backgrounds. My informant pool included: travel health professionals who specialize in treatment of infectious and tropical diseases; scientists specializing in HD research; a dermatologist; and one nurse. This variation in informant background is why I use the phrase healthcare professionals and not the word physicians throughout my thesis. Half of the interviews were conducted in-person while the other half was conducted over the phone. The interviews were audio-taped with the permission from the informants and transcribed. These interviews were further supplemented by participation in an online NHDP training program and extensive library research. This study is part of a larger project that focuses on immigrants and health, particularly immigrants with HD, being conducted by Dr. Cassandra White from Georgia State University (GSU). Dr. White also acted as my advisor. This study is based on what has cumulatively been approximately two years of research on, and experiences working with, immigrants and refugees during my Master's degree training.

Patient Demographic

There are many endemic cases of HD in the U.S.; however many patients who have been treated at the clinics are immigrants or refugees coming from endemic countries. The country of origin for the clinics patients included Brazil, Vietnam, Mexico, Pakistan, several countries in sub-Saharan Africa, The Marshall Islands and the U.S among others. However the patient demographic differed at each clinic. The two clinics in the Southeastern U.S. had primarily Mexican and Brazilian first generation immigrant patients. The NHDP clinic, in the Gulf Coast, had primarily American-born patients. The final clinic was in the Northwest U.S. and that clinic saw many Asian immigrant patients but also noted having patients born in Brazil or Mexico.

The number of new cases in 2010 is expected to be about 260 (Microbiologist Informant 2012), though this was not officially published at the time of my interview with the informant who disclosed this information. This number is up from 2009 when there were approximately 160 new cases known. The total number of cases has been slightly higher the past few years with cases endemic to the U.S. being associated with spread through contact with armadillos, a finding which has only recently been confirmed by NHDP program scientists (NHDP 2011). Additionally, the NHDP program attributes the rise in known new cases to increase in disease detection by physicians due to NHDP extensive efforts to educate healthcare professionals on how to identify the disease. Despite the changing demographics of the patients, with a rise in native-cases, the majority of HD patients in the U.S. are still immigrants (WHO 2011).

While any physician could be trained to treat a HD patient, as one informant stated, “most physicians do not recognize the disease that is staring them in the face” (Microbiologist Informant 2012). This is the circumstance the NHDP has focused their education efforts and pa-

tient advocacy on by training healthcare professionals through awareness seminars. Many of these seminars have taken place at the 13 federally funded ambulatory clinics, but they have conducted these seminars in several other locations. I participated in an online version of one of these seminars focused on preventing advancement of the often debilitating effects of neuropathy.

Terminology: Immigrants, Migrants, Refugees, Aliens

It was difficult finding consistency in the criteria anthropologists have in their use of certain terms to describe immigrants. I have decided to include this discussion in my methodology because it helps define the group that is the subject of inquiry in talking to healthcare professionals. It was crucial to explore inconsistencies and to then establish consistency for this study. Within anthropology the nouns immigrant, migrant and refugee imply an achieved identity. This identity is used to distinguish an individual who is living in a country that is not their country of birth from native-born citizens. These terms are often used interchangeably. These individuals are further identified by another attained status by the adjectives documented/undocumented or legal/illegal. There are varied forms of documented or legal status, all of which implies varied levels of rights the individual has. To be documented, or to be here legally, means an individual has applied and been approved for an immigration visa. This status allows an individual to eventually become a permanent resident by receiving their green card, eventually allowing them to become a U.S. citizen. Other types of visas exist that allow for temporary stays including for business, tourism, studying, and work. To be undocumented, or illegal, implies either the

proper documentation was not applied for entry into the U.S. or an individual's visa has expired or been revoked.

The word alien, which is used in the U.S. Government (USG) immigration laws, is also sometimes used, but typically in a derogatory manner. However, the word alien has been used by the USG not with the intent of insulting individuals, but as the "antithesis" to citizenship (Coutin 2005:281). According to Coutin (2005) citizenship implies a bound between the individual and the law, which was established through swearing allegiance to the Constitution or by being born in the U.S. An alien was an individual that was not bound to the law. However, over the years this term has become offensive and is not used within anthropology to identify an individual or their status.

The terms immigrant, migrant and refugee are used interchangeably in most of the literature I used for background research for this study. I did a literature review to aid me in establishing an ethically sound reason for choosing to use the word immigrant. This literature included primarily anthropological sources but was also interdisciplinary pulling on research from geographers and sociologists. A refugee is any individual who receives political asylum because of being forced to leave their country due to persecution, and war or violence due to religion, race or nationality (UN Refugee Agency 2011). However, refugees are also considered to be immigrants and sometimes the terms are used interchangeably. Searight (2003), while discussing Bosnians' perceptions of the U.S. healthcare system, refer to the Bosnians as refugees and immigrants. Upon closer evaluation one notices that Searight (2003) refers to the Bosnians more readily as immigrants as opposed to, what he identifies as a contrast to refugees who come from least developed countries (LDC's). The distinguishing factor for Searight (2003) is

that the Bosnians have had better access to medical care whereas refugees may not. Searight (2003) is implying the degree to which you are a refugee depends on how developed your country of origin was and subsequently general living conditions.

The word migrant was used to refer to any individual that moves from one place to another, often for work or pleasure travel within their country of birth or between two countries. The word migrant has also been referred to as the actual process of moving (Potter and Phillips 2006; Brettell 2003). The term migrant is more commonly used than immigrant with the increase in transnational migration, as people move back and forth between countries. This has resulted in the more frequent use of the term transnationalism to describe individuals who maintain strong connections with their country-of-origin (Alfred 2010). The more frequent use of the term can be attributed to increased access to "communication, media and transportation technologies" (Alfred 2010:219).

The term transnational has not always been defined by these technological communication connections. Randolph Bourne (1916), who is credited with coining the word transnational, states in his article *Trans-National America* that transnationalism was the ability to resist assimilation and instead embrace enculturation. This process would allow Americans to maintain a sense of its heterogeneous cultural identity which would help the country thrive (Bourne 1916). Through this analysis it becomes clear that the meaning of the terms do change over time, as well as what is implied by them. Even with these articles, the words immigrant and migrant are used interchangeably to refer to the individual. Casteñeda (2010) combines the terms immigrant and migrant into im/migrant in order to capture their shifting and often cyclical (for seasonal workers) relationship. For this study, I have decided to use the term immigrant

because I feel it speaks more broadly to the status of the individual who is living in a country that is not their country of birth. This status applies to both migrants and refugees. Throughout this study, I will indicate migrant or refugee specifically if the individual's status is unclear or important to note. I recognize that my research proposal used the term immigrant and upon distributing this information to my informants to review, in order to agree to participate in my study, could have been leading them to use the term immigrant. However, except for one occasion, my informants consistently used the term immigrant.

Why Healthcare Professionals?

The original focus of this study had been on immigrant HD patients' treatment-seeking behavior and experiences. I had also intended to seek out information on the incidence of co-infection, of HD and other diseases or illnesses, and if, this condition complicates treatment-seeking. However, I was not able to gain approval to interview patients; although I had IRB approval to do this, the clinic where I began my study would also have required their own institutional IRB approval for physicians to introduced me to patients. Due to this, the study was refocused to capture perspectives of healthcare professionals on treatment of immigrant HD patients.

My questions were designed to capture healthcare professional perspectives of treating immigrant HD patients. However, one informant told me that each clinic may only have 2-4 patients at any given time. Given this, and knowing that the experience the healthcare professionals had at the clinics varied, questions were designed to intentionally elicit a response on the cumulative experiences physicians may draw on when treating immigrant HD patients. Such

questions included: What considerations do you take into account when treating immigrants?; What experiences do you have treating HD? If none, what experiences from your training might you draw on to treat HD? What experience do you have treating neglected tropical diseases (NTD's)? Will you draw on these experiences when treating HD immigrant patients? What social/cultural considerations do you take into account while treating HD patients? Are there additional considerations when patients are also immigrants? A full list of interview questions can be found in Appendix A. While my questions successfully motivated discussions on immigrant HD patients, my informants seemed cautious in their responses. I attributed this to what Nader (1972) termed studying up.

Studying Up

Studying up is a phrase that was coined by Laura Nader in the 1960's in reaction to Nader's belief that anthropological inquiry should extend beyond the underdog. It is based on the premise that "the quality of life and our lives themselves may depend upon the extent to which citizens understand those who shape attitudes and actually control institutional structure" (Nader 1972:284). In my study, healthcare professionals at the clinics are responsible for effectively utilizing their resources to treat and cure HD patients regardless of immigration status.

In studying up Nader (1972:289) says you must ask the "common sense questions in reverse." In a studying down perspective this question would ask: how is the utilization of resources affecting (knowingly or unknowingly) the patient outcomes? But, in a studying-up perspective it asks: how do healthcare professionals perceive the utilization of these resources to affect patient outcomes? These questions become important as the healthcare professional

self-analyzes the effectiveness of their programs and utilization of their resources. Nader (1972) further argues that without studying in all directions someone is left out of the equation and therefore a piece of the whole picture will always be missing. Without all sides of the phenomenon under question, one cannot effectively communicate how these systems work. Since the NHDP has focused the majority of their resources on healthcare professionals' training, I felt it was useful to obtain the perspectives of the healthcare professionals. Studying-up has sometimes been deemed irrelevant due to what Nader (1972:301) terms difficulties surrounding "*access, attitudes, ethics, and methodology.*" However, the relations of power, and how individuals interpret and interact with that power in terms of *access, attitudes, ethics, and methodology*, have become topics of inquiry in anthropology since Nader first wrote about studying up in the 1960's.

Interviews

I conducted eight interviews. Three of the interviews were with healthcare professionals working at clinic that recently received NHDP funding. These informants included two physicians and the clinic's head nurse. These interviews served the purpose of helping me to understand how the clinic functioned, what my informants' experiences were treating immigrants and HD patients, and the importance of the NHDP funding for patient treatment. Three interviews were conducted with NHDP staff. These informants included a physician, a microbiologist and a pathologist who all had varied types of interactions with patients. These interviews served the purpose of providing more thorough background on the history of HD treatment in the U.S., establishing a better understanding of the disease, and soliciting advice on successful

program implementation. I also interviewed a dermatologist working at a NHDP clinic in the Northwest U.S. who had over 40 years of experience treating and working with HD patients. Finally, I interviewed a physician who recently left a NHDP funded clinic but was still seeing some of the same patients at his new clinic. I attempted to interview a NHDP social worker as well as the government official in charge of distributing federal funds for the NHDP and associated ambulatory clinics however I did not manage to make contact with them.

Access

Access was defined by Nader (1972) as those in charge of institutions being out of reach, resistant to being studied, dangerous to study, and difficult to schedule time with. Part of the solution Nader (1972) proposes, is that of building rapport. Luckily, I had worked on a different project focused on understanding the importance of travel health at one of the clinics in the Spring of 2011. Dr. White introduced me to a physician who she had been in contact with for the project of which my thesis is part of focused on immigrant health and HD. Dr. White was also able to put me in contact via email HD specialists at the NHDP with whom she has also worked. These individuals provided me with background on the history of the NHDP as well as the history of HD in the U.S. These specialists also provided me with a unique insight into the microbiology of *Mycobacterium leprae* as well as national level initiatives the NHDP was directing to raise awareness among physicians and other frontline healthcare providers. Surprisingly, these individuals were not difficult to schedule meetings with. The physicians were eager to share their responses about HD treatment. Some of the challenges that Nader discussed in terms of access did not apply to my study.

Attitudes

The issue of attitudes is based on Nader's (1972) beliefs that anthropologists prefer studying the other. However, given her piece was written in the 70's much has changed within anthropology that has shifted the focus many anthropologists have to a more reflexive role involving the reflection on the role of the researcher as well as the researchers own communities. Anthropologists are no longer convinced that pure objectivity is possible and instead recognize that the researcher invariably affects outcomes by their mere presence. Nader (1972) also argues that traditionally anthropologists have not concerned themselves with social reform. Again, however, I argue that this has also changed especially with the development of what is often referred to as the fifth subfield called applied anthropology. Singer (1995) is critical of the ideas of social reform within anthropology and instead suggests anthropologists act as advocates at the community level and evaluate anthropology *in* health not *of* health.

Ethics

Nader (1972) questions whether the same ethical considerations need to be considered for studying up that are considered for studying down. She goes further to clarify, though informant anonymity is crucial regardless, a distinction between public and private sectors of informant involvement should be noted (Nader 1972). In this study, all of the informants' names and job capacities are publicly available on the internet. As each of their job capacities differs, it was much more important for me to consider the use of pseudonyms. The difficulty I had in protecting identities was clear to me from the start. Every informant knew each other by name and simply saying I was working at a clinic in a specific location would reveal to other informants exactly with whom I was working. Therefore, it took careful consideration when removing

as many identifying characteristics as possible without taking away from the content of my thesis. Due to this, I have chosen to conceal the location of my clinics. I battled with this decision because offering analysis at a local context was important, but to maintain informant anonymity I decided to risk criticisms of the lack of such an analysis for the sake of my informants. In addition to these considerations, my research was approved by the Georgia State University Institutional Review Board (IRB). First I was approved to interview patients, but with the lack of access, Dr. White and I submitted an amendment to work with physicians.

Methodology

The final consideration Nader (1972) emphasizes as problematic in studying up is methodology, particularly participant observation. As Powdermaker (1966:287 *in* Nader 1972) emphasized, participant observation is about "physical proximity," "knowledge of their language," and "psychological involvement." Participant observation has been a defining characteristic of anthropology since its inception; however such access is often very restricted in field sites of studying up. Nader (1972), and others, including Gussow and Tracy (1971), suggest that we not feel shattered when such opportunities are not available and instead be creative and remember there are other methods that may be more useful for our objectives. Alternative suggestions include use of documents, memoirs and other creative avenues.

One such creative avenue I discovered was to take one of the NHDP awareness seminars. Though they have many throughout the year only one was available during the period of my research. The course was called Lower Extremity Amputation Prevention in the Neuropathic Limb (LEAP). The course, though focused on treatment and prevention for diabetes patients, developed out of the treatment program Dr. Paul Brand developed for plantar ulceration for HD

patients. In advanced stages of HD patients experience neuropathies, or desensitization of the nerves. In areas where nerves are desensitized patients are known to be much more vulnerable to injury or chronic inflammation leading to infection. The program had four main objectives: 1) understand the conditions associated with amputations; 2) understand the five elements of the LEAP programs; 3) identify patients according to the risk categorizations; and 4) be able to explain the components of self-management. Though I had no direct contact with anyone, just being part of some of the training physicians go through was an important field experience. It was also a turning point where I saw how important it is for patients to be able to access treatment as advancement of the disease can lead to serious disfigurations. Such disfigurations would only contribute to the challenges patients face including stigma.

Analysis

In order to make sense of the data I collected I qualitatively coded my interviews for interpretation. This involved distinguishing consistent themes within each interview. Such themes included: treatment, diagnosis, coinfection, training, history, funding, area specific information, referrals, immigrants, and stigma to name a few. Other subcategories were made within each of the primary categories. This allowed me to cross-reference conversations and piece together a cohesive analysis of how healthcare professionals understand treatment-seeking experiences. After performing this coding activity, and reading through my interviews multiple times, I finally began to see that the healthcare professionals recognized challenges, both internal and external to the clinic, that patients encounter when accessing treatment.

3 SEEKING TREAMENT: GETTING TO THE CLINIC IS HALF THE PROBLEM…..

> "Most physicians do not recognize the disease that is staring them in the face" (Microbiologist Informant 2012).

Restricted and limited access to healthcare is the primary barrier contributing to decreased quality of health for many immigrant groups (WHO 2008; Collins et al. 2002; Reitz 2002). Many of these challenges are experienced by patients during the process of seeking healthcare services in the U.S. healthscape. The healthcare professionals I interviewed were aware of challenges immigrant patients encounter outside the clinic. The experience that some immigrants have when accessing healthcare in the U.S. differs across the socioeconomic spectrum. Such experiences are dependent on level of education, occupation, and income (Castro et al. 2010). Experiences can also be attributed to cultural particularities that economic and political conditions of the healthscape may inflict on certain immigrant groups. My informants noted such differences among their patients.

Immigrants entering into the U.S. with a formal education, and the associated skills, often enter society in a higher income bracket making healthcare expenses more affordable if a private plan is not offered by their employer (Castro et al. 2010; Hall et al. 2011). An additional sub factor could also be country-of-origin as such experiences could differ. One healthcare professional noted this difference among his patients. He classified most of the immigrant patients in his clinic as being in a lower socioeconomic bracket. He further noted many of his 'Asian' patients were better off financially than Brazilian patients, and clarified many of the latter were undocumented migrant workers who have a low household income. Among his 'Asian' patients he further clarified patients from The Marshall Islands, Samoa and Vietnam often enter the U.S.

in a lower socioeconomic background. One healthcare professional went as far to recognize that discrimination may be based on ethnic appearance, stating that an assumed ethnic categorization was an underlying risk factor when accessing healthcare services.

Just as factors such as education level and associated skills, and subsequently income, can be indicators of risk factors for health status, other factors may be involved. The Multi-Ethnic Study of Atherosclerosis indicated that low education was a risk factor for the chronic condition of coronary calcification among Whites (Castro et al. 2010). However, education was not an indicated risk factor for Chinese Americans in the same study (Castro et al. 2010). Similarly, The Filipino American Epidemiological Study indicated that chronic health conditions and psychological distress were not linked to education or income for Filipinos as other factors such as "subjective social status and economic opportunity" were linked to higher health outcomes (Castro et al. 2010:600). Though education and income were not risk factors for certain chronic conditions among these groups, education and income do influence health status in other ways. In my conversations with medical interpreters who work with Vietnamese and Cambodian immigrants, patients often delay accessing healthcare services for fear of not understanding what the physician says, as they tell the interpreter they are not as educated as the physician. Even if an immigrant has received a high-level education in their country-of-origin, certain types of degrees are often not translatable in receiving countries.

In a flight I took to California from Washington, D.C. a fellow passenger went into cardiac arrest. Luckily, one healthcare professional was on the flight, a physician from Vietnam who was currently living in the U.S who was sitting next to me. However, he was legally not allowed to help the passenger. In conversation with him I was informed if he had touched the man he

could have lost all chances of practicing medicine again because he was not a board certified physcian in the U.S. In additional conversations with him during our emergency landing I found out how frustrating this was for him not only ethically but also in terms of, what he called, a downgrade in his social status and economic stability, or occupational downgrading, as his skills were not translatable across international borders. Immigrant status is differentially experienced and extends beyond socioeconomic factors. Language, ethnic and racial identity, religious beliefs, and gender roles are a few cultural and linguistic factors that might affect the treatment-seeking experience of some immigrants in the host country. Many of these additional factors will be discussed more thoroughly in the context of patient-healthcare professional interactions in the next chapter.

Complications of U.S. Healthcare

The healthcare professionals I interviewed estimated that about 50% of their immigrant HD patients have some form of health insurance. Most that do have insurance have Medicaid. This type of health insurance is a USG program for families and individuals in a lower income bracket (Medicaid FAQS 2011). Most states offer Medicaid funding for limited benefits for both documented and undocumented individuals. These limited benefits include emergency and labor delivery services (Medicaid FAQs 2011). In 1996 the Personal Responsibility & Work Act strictly limited access for even documented immigrants. This Act was established as part of the welfare reform legislation that made documented immigrants ineligible for Medicaid for the first five years of their residence, starting with the date that alien status is declared (Derose et al. 2007). The same limitations became part of the State Children's Health Insurance Program

(1997), which serves the purpose of providing coverage for children whose family income is too high to allow them to qualify for Medicaid (King 2007). In these examples, policy becomes a means to reject a deterritorializing community with ever-increasingly heterogeneous needs.

Access to health insurance plans can be further complicated by bureaucratic processing as eligibility requirements are confusing and difficult to understand. In my work with refugee women the biggest challenge in accessing these plans is understanding the procedures for gaining the documents required to enroll. These documents include a social security card, picture ID, and a renters lease. These forms of documentation become social capital that governs access to healthcare resources through institutionalized exclusion. This exclusion has been institutionalized as our country reinforces citizenship status through multiple forms of identity, some of which are difficult to obtain for those who were not born in the U.S.

The unfamiliarity with the healthcare system in the U.S. is the primary reason Mexican immigrants return to Mexico to seek care in a culturally familiar place (Chavez 2003). Crossing back over the border is seen as an ideal alternative to navigating a complicated healthcare system in the U.S. Even when health insurance is acquired, the "many confusing, abstruse elements of managed care, such as capitation, utilization review, prior approval, physician incentives, gag rules, and copayments" (Flores et al. 2004:336) are seen as yet another barrier in accessing services. While my informants recognize that some patients do return to their country-of-origin, they were unsure of the circumstances that lead to such decisions.

An additional component of the challenges of accessing treatment in U.S. healthcare system is highlighted by Searight (2003) who discusses how primary care centered U.S. care plans do not match Bosnian models of healthcare. These differences present confusion for

some Bosnian immigrants. In Bosnia primary care physicians are accessed only for emergencies. Community centers act as secondary care and tertiary care is provided by teaching or university hospitals (Searight 2003). In contrast, primary care physicians in the U.S. act as gatekeepers to specialized care as governed by care plans that require referrals for specialized care.

When adequate financial resources to cover costs are not available, treatment-seeking is often delayed or avoided for fear of incurring large debts. While volunteering at a local school for refugee women, where I primarily worked with Cambodian refugee women, families often delay seeking-treatment for fear of not having the income to pay for services. Many of these women's families work in a local chicken factory, and their income is not very substantial. As a young Mexican women noted in an interview about her experiences with breast cancer in the U.S., "here [in the U.S.] cures are expensive" (Chavez et al. 1995:57). Similarly, one of my informants noted that his patients from Thailand are outraged at costs because in their country you can go to the hospital and pay five dollars and be treated. My informant and I joked, that would barely get you into the parking garage in some areas of the U.S.

The Context of the Healthcare System and the Clinics

Each of these challenges -- education, income, and documentation status was -- identified by my interviewees as relevant to the overall experience of treatment-seeking for HD, but such factors, as one informant said, "do not influence what I do." Simply put, the healthcare professionals said none of these factors influenced how they interact with patients nor did it direct how they treated their patients, even though a patients' circumstance could influence what the healthcare professional has to do to help their patients. Knowing about their patients,

where they came from and background helped the healthcare professionals relate better to their patients' needs. In fact a few of my informants stated they entered into their specialized field, either infectious and tropical diseases, research or dermatology, because they felt their skills and passion to help would be better suited for answering to the needs of patients who may be marginalized.

Each of the clinics have resources they can offer their patients, especially in the case of the three NHDP funded clinics. Many sources of funding are available at each of the clinics. Three of the clinics in my study receive unrestricted funding from the NHDP. This funding covers all aspects of treatment including visits, laboratory tests, medication, and therapy. Two of these three clinics are attached to private healthcare systems and have other sources of internal funding to cover patient costs. The fourth clinic is also part of a private healthcare system and the informant there stated they can cover most treatment costs as well as reimburse patients for travel and meal costs. Some NHDP clinics, according to a source at the NHDP, even have funding for transportation. After language barriers, which will be discussed in more detail in the next chapter, transportation was the number two factor identified by healthcare professionals as contributing to difficulties seeking-treatment. Healthcare professionals at three clinics (two NHDP funded, one not) stated they had funding that could cover transportation costs, so that may not be a barrier. A healthcare professional at another NHDP clinic stated they could no longer cover transportation costs due to rising costs. The exact costs that were rising were not specified. However it was implied that the current state of the U.S. economy was to blame for that.

It should be noted that transportation as a challenge extends beyond costs. One healthcare professional noted it is also important to realize some immigrants do not qualify for driver's licenses. In these cases, patients rely on family members or public transportation, if accessible where they live, to attend clinic appointments. The same healthcare professional noted family members who can drive may not be available at the time of the visit because of work. Understanding such situations is important when patients are evaluated for their routine follow-ups, which will be discussed more thoroughly in the next chapter. However, I will also note that a few healthcare professionals did recognize that an underlying issue is that patients cannot always take off work or may work non-traditional hours that would not allow them to visit the clinic during the traditional 9:00am-5:00pm workday hours in the U.S. In one case, a healthcare professional noted taking one day off work to come to clinic could result in the individual not being able to feed their family for the week. After work hours options for medical help are almost exclusively limited to visiting the emergency room, which can cause a variety of additional problems such as expenses that might normally be covered by clinic funding, fear of exposure of documentation status (if the patient is undocumented), and in the case of HD a healthcare professional may not know what HD is or how to treat the disease. One informant noted she felt such clinics should be open through the late evening to accommodate such scenarios.

Being available and present in a local community, however, is not enough to get the patients to the clinic. A common theme throughout my interviews was that, in general, healthcare professionals who have not received specialized HD training, or that do not have experience treating patients have knowledge gaps. Healthcare professionals either do not know what the

disease is or think they know but have misconceptions. For the former, healthcare professionals from the NHDP perform community outreach and patient advocacy seminars. These seminars focus on providing biomedical information about the disease for healthcare professionals to help diminish the likelihood of a delay in diagnosis. Another NHDP clinic in the Northwestern U.S. has also conducted community outreach. The latter point is referring to what happens when healthcare professionals know what the disease is but are conflicted about treating the patient because of the misconceptions the disease. This often results in HD stigma influencing the overall patient-healthcare professional interaction.

Physician Knowledge

"Most physicians do not recognize the disease that is staring them in the face" (Micro-biologist Informant 2012). This was the line that captivated me the most during my research. It was an unnerving reality for this line to come out of the mouth of HD specialist. While most of my research focused on healthcare professional perspectives of immigrant HD patients, the side conversations and tangential stories reflected a frustration within my informants that war-ranted sharing. My informants emphasized that the general lack of awareness, or knowledge gaps of HD among healthcare professionals was a serious challenge for patients. Among my eight informants, there was a broad range in terms of level of experience treating HD patients, but most of them specialized in either HD research or treatment of tropical and infectious dis-eases. My informants were compassionate about helping their patients. However, all of them discussed how awareness of the disease is a major roadblock in treatment-seeking experiences. While my informants noted that getting to the clinic was half the challenge for patients, there

were many identified issues that occur within and outside the clinic within a healthcare setting. My informants had examples of what happens when knowledge about the disease is not present and when the knowledge that is present is often based on subjective mythical, Biblical and imperialistic understandings of HD. To paraphrase one informant, it is one thing to know nothing about the disease, but it is a totally different thing to claim knowledge that one does not have.

When it comes to knowing the disease, there are two types of 'knowing'. One type is simply not knowing about the disease. This lack of knowledge can be a roadblock to patient-healthcare professional interactions, often leading to delay in diagnosis. The second type of 'knowing' is when only part of the story of HD is understood, or what I am calling knowledge gaps. What forms these knowledge gaps is when the healthcare professionals is aware of HD but such knowledge is situated on mythical qualities of the disease where stigma marginalizes patients in their interactions. My informants challenge medical professionals to think beyond their subjective understanding of the disease, as many of these perspectives are not based in clinical knowledge, but popular beliefs.

Before continuing it is important to note that HD cannot be transmitted through blood. The bacterium lives in the cool environment of the nasal passages. Additionally, only a small percentage of people are at risk for catching the disease if exposed. Certain genetic predispositions could make individuals more vulnerable if exposed to the disease for prolonged periods of time, such as living with someone with HD. One story I would like to highlight, related to me by one of my informants, is the story of a patient with an injured tendon. This patient had to be referred to an orthopedic specialist for surgery. The tendon had been injured from minor ad-

vancement of the disease and the tendon needed to be fixed. The orthopedic surgeon called my informant to inquire into why he had sent him a 'leprosy patient'. The surgeon was concerned for the safety of himself and his team. My informant had to explain to the surgeon why he did not have a need to worry. While the surgery was performed, my informant noted that the operating room was closed longer than normal protocol to sanitize the equipment. My informant concluded by emphasizing the sometimes bizarre ways in which physicians react to cases of HD and how these reactions are stigma-inducing.

Such a reaction is often driven by subjective notions of the disease as being highly contagious. One patient was brought to the hospital to be treated for reactions. Reactions are caused by dead bacteria in the body of the patients who have completed treatment for the disease and been cured. My informant noted that the nurses did not want to enter the room to check on the patient. Subsequently, the patient was mostly left to fend for themself. When the nurses did enter, they entered wearing bio-safety masks and gowns, the kind you might see the Centers for Disease Control officials wearing when they handle anthrax or avian influenza. My informant reflected, these nurses work on an infectious disease ward, "for Christ sakes it's 2012." Other informants shared similar stories and conveyed similar reactions. "Pick your disease," they said. My informants noted they work in clinics that treat patients with tuberculosis, HIV/AIDS and other highly infectious diseases, so why worry so much about HD?

It is also important to document the perspectives of other actors in the treatment-seeking experiences. Administrators and hospital managers are as much engulfed in these same issues. One informant shared with me that a patient had visited a hospital to get a lesion checked. Upon diagnosis, the patient was promptly escorted out of the hospital and asked not

to return. Similarly, one patient had the V.I.P. treatment of having an elevator to himself for the day, as it had been shut down by the hospital administration to isolate potential contact with others.

Finally, stigma exists even within the clinics that specialize in HD treatment. One informant shared with me how the floor manager, on a floor that houses a travel clinic, a HIV/AIDS clinic, and geriatrics practice, approached him asking why he was treating 'lepers'? It was not long after this encounter that this physician left the hospital, and many of his HD patients followed. As one informant implied, at least you can talk to other healthcare professional on a biomedical level about the disease. Such a conversation may be more difficult to have with someone, such as a hospital administrator, who may have less knowledge of such biomedical processes.

While these stories may seem extreme, they are a reality for many patients who seek treatment for HD. The stories thus far document what happens when knowledge gaps exist. This 'knowledge' is often wrapped up in mythical qualities and popular models of the disease as being highly contagious and dangerous. In these examples the patient becomes a dangerous vector for disease and therefore is seen as someone who must be avoided and treated as such accordingly. The patient is set apart from others, as done in Old Testament Biblical accounts of the "leper" being cast out of society. The boundary of safe and unsafe is drawn with protocols for sanitation and physical barriers that protect the healthcare professional at the patient's expense.

I will conclude this chapter with a hopeful story of what is being done to diminish the cases of general lack of awareness of the disease. The healthcare professionals I interviewed at

the NHDP discussed their efforts on awareness seminars they conduct at medical offices across the country. These seminars are focused mostly on the clinical aspects of the disease. My informants noted that if they can get any message across it would be through biomedical evidence presented by research specialists who inform healthcare professionals why they do not need to worry about the disease. Healthcare professionals at another NHDP clinic also conduct awareness talks in their local community.

Officials note that what is most important is training the eye to see the disease. One informant shared a story about a patient encounter they had at one of their seminars. Upon walking into the room, my informant could tell the patient had HD. The disease had advanced so far he could diagnose the patient from across the room. The informant pondered how this patient had not been referred to a specialist to be seen and treated. This is especially since early symptoms, particularly insensitivity in a skin spot or other loss of sensation, should be easily recognizable to doctors with even minimal training. Additionally, HD is the only disease that causes this type of neuropathy. So as much as filling in the knowledge gaps is about debunking these myths, it is just as much about advocating for informed knowledge.

With these examples, it begins to appear that the confounding factors of healthcare professional knowledge and stigma are influential factors that create challenges for patients accessing healthcare services. Attaining a diagnosis can be delayed for anyone, regardless of citizenship status. While the healthcare professionals spoke about both immigrant and native cases among their patients, they did continue to note that the majority of cases are among immigrant groups. There are many challenges that are specific to immigrants in seeking treatment. Additional complications such as general lack of knowledge among the healthcare pro-

fession about the disease only makes these experiences more difficult. The primary care physician a patient might initially see governs access to specialized care since managed care plans require referrals for specialized care. Brazilian immigrants have had similar experiences when accessing health services in the U.S. Many Brazilians state they believe if a healthcare professional cannot diagnose a problem they are responsible for referring them to someone who can (Roberts 2007). One Brazilian patient stated that neglect from healthcare professionals to diagnose and treat resulted in them returning to Brazil to "seek a diagnosis from a competent physician" (Roberts 2007:194). This study is relevant to my study because every clinic treats Brazilian immigrants and Brazil is second in the world for HD incidence where over 30,000 new cases are reported every year (WHO American Region 2006).

Once patients reach clinics where physicians are trained to, or have experience diagnosing HD they are immediately diagnosed and treated. However, getting to the clinic is half the problem in treatment-seeking experiences. While there are challenges associated with being an immigrant with the disease, the biggest challenge comes from having such a highly stigmatized disease that is still not understood completely. As patients seek treatment the biggest barrier external to the clinic appears to be the knowledge healthcare professionals have of the disease. Closing this gap in knowledge will become more crucial, not just for HD, but as more and more people move across borders and seek treatment for diseases that are less commonly studied by U.S. healthcare professionals. While getting to the clinic is challenging, there are also challenges internal to the clinic. The next chapter covers how healthcare professionals understand and work to eliminate further challenges for their patients within the clinic.

4 SEEKING TREAMENT: ….BUT WHEN THEY FINALLY GET TO THE CLINIC

"Time. Spend more time. Learn about different cultures."
(Physician Informant 2012)

I had the chance to visit one of the four clinics from which I drew my sample of healthcare professionals currently treating HD patients. This clinic is positioned in a downtown hospital that is constantly buzzing with activity. You can hear the city traffic, the valet traffic and the bustle of the lobby upon walking in, all of which is slightly disorienting. There are no signs indicating which direction to go specifically for the clinic, and unless you looked it up or someone told you which floor the clinic is on you would have to ask (if you are proficient in English) the help desk personnel located directly in front of the entrance. I have never been on the elevator alone and often times the ride to the floor is discombobulating as a mixture of patients, family members and healthcare professionals carry about their conversations or awkwardly reach forward and around people to press the button for their desired floor. My desired floor houses the travel clinic, the infectious disease clinic and a geriatrics clinic - a bit of a mix. Every time I find myself wondering if someone is wondering what trip I am going on, or what infectious disease I have, or what could happen to someone so young they would need geriatrics help.

Exiting the elevator I release all those thoughts and try to orient myself. To the right is the infectious disease clinic and to the left is the travel clinic. I find myself confused because I know HD is considered an infectious disease but everyone I scheduled time with is associated with the travel clinic. I take my chances and go left, wondering if patients get confused. There is

a large front desk that, after a few visits, I realized is not part of the travel clinic and the past few visits I have checked in with the wrong people. No wonder they always make comments "oh that's the travel clinic" and then pick up their phones and call someone. Not to mention the weird looks a 23 year old is getting at the geriatrics check-in desk. The check-in for the travel clinic, though marked, is not prominent against the majestic backdrop of the city out the windows behind the geriatrics check-in desk. Eventually I realize the small office just to my right coming off the elevator is where I should have been checking in all along.

Once I check in I wait for the healthcare professional I am speaking with to come find me in a busy waiting room watching the news. Strangely enough, on one of my visits the news broadcasters were talking about issues of undocumented immigrants. I cannot imagine how awkward that would be if I were an undocumented immigrant watching this broadcast. You may ask, is this likely? The answer is very. This is one of the only times I pray the patients do not speak English let alone see the images of cops rounding up what I assumed to be undocumented Mexican migrant workers. The healthcare professional with whom I plan on speaking comes and finds me personally. I doubt that happens for a patient, but the nurses all seem so friendly so I would not be deterred by these nurses coming to collect me for a medical visit.

Of the three interviews I conducted at this clinic two were in the offices of the physicians and the other was in an exam room with the nurse, who I am sure does not have her own office. The clinic atmosphere is somewhat welcoming. I cannot put my finger on why I feel it is welcoming except maybe because I have been here before and after a first few visits it feels more welcoming. After finishing my interviews with the healthcare professionals, they walk me out to the clinic entrance into the big waiting room where I started with the television. I cannot

help wondering, who would not want to come back? However, this very question is plaguing this clinic. As I hope I demonstrated in my last chapter, getting to the clinic is half the problem. However, the other half of the problem follows.

The Bureaucracy of Filling out Paperwork

If figuring out where to check-in and the flashing of anti-immigration sentiment on the waiting room television would not be an unnerving enough experience for immigrant HD patients at this one clinic, the paperwork may be. Healthcare professionals at all four clinics mentioned something about this process as being one, among many, decision points in treatment-seeking. Some patients continue on, others turn around and never come back. The latter happened at two clinics (as reported by my informants), in both instances the patients were Brazilian immigrants, either known or believed to be undocumented. What is it about the check-in process that leaves patients, as one healthcare professional noted "running out the door never to be seen again?"

Two healthcare professionals expanded on their beliefs on ways the paperwork would produce such anxieties in patients, particularly undocumented patients. One stated that some of these patients had been drilled at other health facilities in the local community about not having a social security number that matches to a known number in the database. Threats of exposure for undocumented patients are common anxieties among immigrant HD patients, as many informants noted. While the healthcare professionals stated this would not affect their treatment of the patient, as they do not personally ask the patient, this has not kept the encounters with office staff requesting documents be filled out to be less stressful and anxiety

producing interactions. At one clinic, the healthcare professional noted as financial hardships increased over the past five years the clinic had to financially account for how the funds for their free treatment were being used as part of the hospital's system of within which the clinic operates. This resulted in all patients who were using such funds to be required to go through financial counseling where detailed information of their financial and employment history are collected by hospital staff. While the physician noted this screening does not result in undocumented immigrants being reported it is an unfortunate policy the hospital has implemented that produces anxieties for patients. He further clarified we have to make sure someone is not coming in with insurance that just does not want to pay a deductible or co-payment.

While the idea of free treatment is enticing, some such programs elsewhere, and not specific to HD treatment, have been notorious for providing financial services that are contradictory in "the impulses of exclusion and generosity" when patients are immigrants (Hoffman 2006:237-238 *in* Castañeda 2010). For example, according to Horton (2004), upon visitation to a clinic in Albuquerque, New Mexico, certain groups of immigrant patients are normalized into classifications of behavior categories as deserving or undeserving patients based on documentation status. This classification is said to "oscillate between liberal generosity and stringent rationing depending on the political economic climate" (Horton 2004:475). One cannot argue that each state in the U.S. has its own political and economic climate that account for difference in treatment of many immigrant groups. However, the categorization often results in a discrepancy in how Cuban refugees versus Mexican immigrants were treated in New Mexico (Horton 2004). In this case, whereas the refugees were brought to the community by the federal government and understood as legal, the immigrants were assumed to be undocumented (Horton

2004). This discrepancy was evident because where Cuban refugees were eligible for support services provided, Mexican immigrant were expected to pay up front for services (Horton 2004).

While it is clear that immigration status and financial burdens produce anxieties for patients, the language and cultural barriers are felt as severely. If the patient is a Limited English Proficiency (LEP) individual the task of filling out the paperwork could be difficult and produce further anxieties as the paperwork is in English. Medical interpreters I spoke with for a past project professed their frustration that often their visits only started in the exam room stating they should start the minute the patient walks through the door.

Nurses on the Forefront of Patient Interactions

After the patient encounters the office staff while filling out paperwork and checking-in at the travel clinic/HD clinic where I spent time, patients next see the nurse who brings the patient to exam room. Nurses are on the forefront of patient treatment. The NHDP recognizes the important role nurses hold as both advocates for patients within the clinic and in the community. As one informant stated “you have to educate those who are spending time with the patient; the nurse” (Microbiologist Informant 2012). Nurses take not only take vitals of patients as they would in a typical doctor’s appointment, but they take the patient’s history that is often critical in establishing what the patient is at-risk for. Risk categories travel history, country-of-origin and vaccine history. These simple categories reveal to the nurse the beginning steps of a work-up a physician may need to perform in diagnosing the patient’s ailment. Not only does this initial collection of patient history allow for a starting point for patient diagnosis, it also

serves as the beginning of a relationship built on trust and understanding that flourishes in a comfortable environment (Nurse Informant 2012). Since I formally interviewed only one nurse, I cannot speak directly to how their role may or may not influence the patient experience. However this one nurse was the only one in the clinic to have attended the NHDP two day seminar, though others at the clinic do plan on attending.

In Arkansas, as mentioned in an earlier chapter, there is a large Marshallese population. In this community nurses have been critical frontline health workers who engage with their community to identify those at risk and those suffering from various ailments. The state's health department hired a few Marshallese nurses who are well respected by their community. These nurses follow-up with patients in their homes where they are warmly welcomed. A few informants knew of this example and shared the story with me. They each noted the success of the nurses in the community has to do with the fact they are Marshallese and the cultural and language barriers are eradicated. While one of their main roles is to follow-up with tuberculosis patients, a model program of community outreach around the world, the nurses are also well aware of the incidence of HD among their fellow Marshallese. My informants who had worked with these nurses noted how invaluable such a role has been in identification of and treatment of HD patients. However, such individuals and the resources to support this type of frontline outreach are not always available.

Time and Availability

Every healthcare professional I interviewed talked about providing time and availability as critical in building rapport with patients. The treatment for HD lasts about two years and may be more if reactions occur. Follow-ups are critical for healthcare professionals to track patient improvement as well as to make sure symptoms are not increasing in severity, specifically neuropathies. There were two components to discussions healthcare professionals had with me about time and availability. One was about providing time while the patient is at the clinic. The other was being available when the patient is not at the clinic or shows up unexpectedly.

Two healthcare professionals discussed how they build trust by providing time. Time was evaluated as a tool to improve the relation the healthcare professionals had with their patients. This is in contrast to many patients reflecting on time as a frustrating component to treatment-seeking. One healthcare professional stated that time is not what most patients have. He further explained that most of his patients were in a low socioeconomic bracket, except two he could recall, and worked to provide for their family. In this discussion he continued to explain that many of these patients, low-income immigrants, some undocumented, could not work their time into a clinic schedule of 9-5 business hours. Many patients worked through the day and into the night, took care of their families and could not escape the duties of their daily lives to make it to the clinic. One patient scheduled four months out because he knew that day would be the only day until then he would be available to visit the clinic for a check-up. This same healthcare professional stated he felt others take these conditions for granted when evaluating the patient-healthcare professional interaction. By simply missing one day of work, a patient could lose earnings that would allow their family to eat that week.

One solution this healthcare professional came up with was to make himself as available as possibly to his HD patients. Upon asking if he felt this was something that should be applied to all patients despite disease, he said that is was not that he did not offer this to his other patients, it was just the HD patients really need that connection with their doctor, and no one else ever took him up on such an offer. He further explained that this is especially the case for patients suffering from reactions. This healthcare professional made himself available to his patients by welcoming them to text message and email him whenever they needed. He noted sometimes patients even send him pictures to ask if the spot of question in the photo should be a concern. This open form of communication allowed him to be available to his patients when they themselves have no time. Another healthcare professional stated that he is constantly available to his patients through his voice messaging service. He stated that his nurses were very good about forwarding messages to him, even when he was not on call. He even mentioned he does not always assign his residents to be on call because he feels his own interactions with the patients are critical in forming understanding patient-healthcare professional relationship.

I asked informants at each clinic about the clinic operating hours. Each of these clinics holds clinic hours either once or twice or week, or once every two weeks. So while healthcare professionals persistently talked about providing time and being available the clinics themselves are open for a very limited amount of time. This is not to say that the availability the two physicians offer through phone services do not improve the patient-physician relationship, I feel clearly they do. However, the clinic structures and regulations put on clinic hours decrease the physical availability of healthcare professionals to patients. This coupled with the patient's

own schedule could make getting to the clinic much harder. One physician stated that his clinic can only be open every two weeks because they have such strict funding. He further noted these regulations will only tighten as the U.S. Government works to tighten its budget.

The open forms of communications the two healthcare professionals offer to their patients through direct electronic communication are ideal for promoting positive interactions with the healthcare system. However, it may be unrealistic to assume the same availability could be offered by every physician. The two physicians who spoke of such communication have been working with HD patients for over 30 years so maybe there is a different dynamic of time that could be analyzed here as well that could be associated with the rapport healthcare professionals build with their patients over the years and growing awareness of their needs in their many years of experience.

PATIENT-HEALTHCARE PROFESSIONAL INTERACTIONS

Every healthcare professional I spoke to highlighted the number one barrier, after transportation, in patient-healthcare professional interactions was language and associated cultural barriers. While many studies rightfully note that ethnic, racial and cultural stereotypes are a leading cause or poorer health outcomes (Farmer 1999; Kleinman 1988; Chavez 2003; Gussow 1989), I argue that while that is often true, there are instances that such generalizations, though based on specific examples, can be debunked. I argue that, healthcare professionals who treat HD patients today, are very well informed of such barriers.

Language was the number one identified barrier to healthcare by my informants. When patients and health care providers do not speak the same language, the quality of patient care

may be compromised (Duffy and Alexander 1999; Bischoff et al. 2003; and Flores 2005). Each healthcare professional I interviewed repeatedly mentioned such barriers as problematic as they tried to form positive relationships with patients. One way in which this is accomplished is by hiring medical interpreters. Many medical interpreters are from the country which the individual they are interpreting for is from. I learned this is done on purpose while attending a medical interpreter training with a nationally recognized program specifically designed for interpreters within medicine. This gives medical interpreters an edge in how the people they interpret for may understand medicine, illness, health and the body. In addition to this, in 2000, President Bill Clinton signed Executive Order 13166 addressing the improvement of access of services for LEP's. Section two of the order addresses that Federally Conducted Programs and Activities are to implement guidelines in the LEP Guidance manual to ensure improved access for LEP's persons (Executive Order 13166 2000). Furthermore the U.S. Department of Justice published a Legal Manual as well as an Investigation Procedures Manual in the case that such programs were reported to not be providing such services.

In 2003, President George Bush provided an extension of Executive Order 13166 identifying who LEP's are as individuals whose primary language is not English and who also have "limited ability to read, write, speak or understand English" (Rosenbaum 2004:94). Additionally, medical interpreters are often trained in how to interpret which includes learning how to speak in first person (as if the interpreter is the patient), body positioning and how to advocate for patients if a complication arises. Informants at each clinic stated they provide interpreters. Informants also stated if an interpreter is not available there is a phone interpreter service that can be utilized.

Some of the healthcare professionals further clarified how use of an interpreter makes it difficult to gain the trust of the patients. It is only through direct interaction that the healthcare professional felt trust is formed. One healthcare professional who is also a first generation immigrant who speaks Spanish and Portuguese fluently is able to speak directly with his patients. As some of my informants knew this individual they spoke of him as an important asset to any such interactions as being from the country many of his patients were from, and being able to speak directly with the patients proved to be invaluable for successful treatment of his patients. This healthcare professional built such a strong rapport at his previous post, that upon leaving it many of his patients followed. He stated that, it was not that he purposefully took patients; they just feel comfortable and knew he understands their dilemmas. This same healthcare professional noted that he does still ask interpreters to be present as certain cultural ideas may be difficult to interpret even with his first-hand knowledge.

Another clinic stated they readily use interpreters. However, the healthcare professional at that clinic said his clinic employs physicians from all parts of the world, many of whom are fluent in many languages including languages from their country-of-origin. While he also recognized the role of medical interpreters he continually emphasized it is just important in HD treatment to build trust and compassion, which you cannot do through another individual; the direct interaction is crucial in forming positive interactions based on trust and compassion. Another clinic stated it is always important to have multiple voices for the patient, even if you can directly communicate. In Thailand one of this healthcare professional's students found in one clinic 20 different terms for HD, and not all the people knew all of them. This brings to light that

a healthcare professional's efforts may not be exhaustive, and potentially can never be, but the awareness is what is key to these interactions.

Recognizing Patient Explanatory Models

Understanding patient's explanatory models is crucial to understand how patient encounters with the medical profession shape behavior and health (White 2005). For immigrant patients the cultural variations in such models could be indicative of whether or not a patient follows-up after an initial visit or if a patient takes their medication, what healthcare professionals often refer to as compliance. However, understandings of disease differ between and within societies (Lazarus 1988). Regarding the example above of how patients in Thailand have at least 20 different variations of how to refer to HD, an informant noted that these words mostly refer to something that can be translated as claw hand (Dermatologist Informant 2012). What he found in his work with these patients is if you said leprosy or HD the patients would be resistant to taking their medications because to them they had claw hand NOT HD. This resulted in the healthcare professionals working with the patients adapting their own biomedical models to say if they did not take their medications they would get claw hand instead of emphasizing the patient has HD. This healthcare professional noted that adapting, broadening one's perspectives, and not enforcing any system of health, whether it be biomedical or folk, are key to communicating the importance of treatment in culturally relevant ways. White (2005) noted such adaptation with patients in Brazil where healthcare professionals negotiate the use of varied terms patients use to refer to the disease. White (2005) further noted the most effective technique was to use a combination of terms when referring to the disease.

My informants stated they mostly use the term Hansen's disease to refer to the disease around non-practitioners (e.g., family members, hospital administrators, etc.) to avoid the stigma associated with the term leprosy. However, as seen in the case above, even using the word leprosy would not have an effect on the patients as it might in Brazil. In Brazil the term *lepra* is wrapped up in folk models associated with loss of limbs or the belief that it is contracted from dogs (White 2005). At one clinic from my study the policy is to not use the word leprosy and instead explain that they have skin infections they will receive treatment for and that it will go away. While the different terminology is important to consider, simply explaining the disease process can be complicated. One informant noted she often had to tell her Dominican Republic patients they had ants in their skin, as a metaphor, because explaining what bacteria was proved difficult (Physician Informant 2012).

These explanations are further extended by additional examples. Common beliefs that spread across different cultures include misconceptions about transmission and contagion. One healthcare professional noted, "scientists have a theory. I'm a practitioner. People want answers and when the doctor is unsure they don't like it" (Physician Informant 2012). This healthcare professional noted that often you know patients have other questions they may be embarrassed to ask such as, can you get HD through kissing or sex? This type of awareness of patient questions comes with years of experience treating patients. Being straightforward is most important. Some patients ask questions about whether it is safe to be around their grandchildren, or for them to work. Often healthcare professionals tell them to not worry so much, because the bacterium is inactivated shortly after treatment begins. In these cases, healthcare

professionals emphasize taking their medications and following-up as the most important criteria in being cured.

Some healthcare professional even adopt syncretic models of health. For example, some patients ask that a shaman/traditional healer be present. These patients have been from Mexico, Micronesia, and West Africa. Patients asked the healthcare professional if they would be willing to work with the shaman to heal them. This healthcare professional noted being flexible allows him to work much closer to his patients. He further clarified, personally, he did not mind this at all as long as what the shaman did does not interfere with what he does. Such syncretic models of treatment are common in chronic health conditions. This healthcare professional said that patients get frustrated with a chronic disease, therefore they look for other avenues to help them cope.

Since it takes two years for patients to complete treatment it is no wonder patients may not always 'comply' with medications. One informant asked me to reflect, asking me if I always finish or comply with a full prescription. I said mostly, but occasionally I have returned prescriptions but that I did not get sick that often. She responded, "Exactly!" Then she continued to ask if I could imagine taking multiple pills, at my age, for two years, every day, different times of the day. Some you take with food, some with water, some you cannot take with milk others you should take with milk. She reflected, "Can you imagine that for two years?" In addition to this, Kleinman (1988:7) says that "chronic illnesses tend to oscillate between periods of exacerbation…to periods of quiescence" making dealing with the illness confusing and frustrating. During this two year period many life situations may change that can exacerbate such fluctuations (Kleinman 1988). Also, with HD the reactions that results post-treatment often leave patients

wondering how they could take the treatment and still have serious problems, leaving them questioning the treatment (Physician Informant 2012; Microbiologist Informant 2012). These reactions are impossible to predict, leaving even healthcare professionals struggling to address their effects.

Trust is Key

Amongst all these discussions the key component to a successful patient-healthcare professional relationship is trust. A few healthcare professionals noted it was imperative that immigrant patients know, if they are undocumented, they will not be reported to Immigration and Naturalization Services (INS) and such a status would not reflect in their treatment. In addition to immigrant status, all of my informants discussed language as being the key factor in building trust. While the use of a medical interpreter is encouraged, the direct interactions the healthcare professionals had with their patients was seen as more important over having an interpreter. Furthermore, assuring patients that cost of care would be covered with additional resources to ease financial burdens (e.g., transportation money, prescription money), was understood as important. However, many of these concerns are experienced before the patient reaches the clinic, making alleviating the burdens of these challenges difficult for the healthcare professional.

5 A CLASSIC CASE OF CATCH 22

> "The colonel dwelt in a vortex of specialists who were still specializing in trying to determine what was troubling him. They hurled lights in his eyes to see if he could see, rammed needles into nerves to hear if he could feel. There was a urologist for his urine, a lymphologist for his lymph, an endocrinologist for his endocrines, a psychologist for his psyche, a dermatologist for his derma; there was a pathologist for his pathos, and cystologist for his cysts. … The colonel had really been investigated. There was not an organ of his body that had not been drugged and derogated, dusted and dredged, fingered and photographed, removed, plundered, and replaced" (Heller 1999:15).

I was reminded of the opening quote for this chapter while trying to recall the concept of a Catch 22. Joseph Heller (1999), author of *Catch 22*, wrote about the colonel character as ward physicians tried to determine what was ailing the poor colonel. Much like many HD patients, when no definitive diagnosis could be determined, he was discharged. Patients are poked, proded, and investigated, often with no definitive diagnosis. Before continuing I think it is important to make clear that while I focused on showing that my informants, healthcare professionals, are aware of challenges immigrant patients face, being an immigrant was not understood by them to be the most problematic issue for patients in terms of treatment seeking for HD. Instead all my informants directly stated or implied that the biggest challenge is a universal problem which has less to do with patient characteristics and more to do with the disease, particularly because of issues of stigma.

A major problem articulated by my informants is that of knowledge of the disease. As stated earlier in my thesis, there are two types of knowledge problems. One type has to do with healthcare professionals who are oblivious to the disease, or as one informant said, it is not one

of the first things that might come to their minds when treating a patient presenting symptoms. The other type of knowledge issue is when healthcare professionals are aware of the patient's condition, but have many misconceptions about the disease, or stigmatizing beliefs. This type I call knowledge gaps because the knowledge that is present is not based on up-to-date biomedical understandings of the disease of which healthcare professionals in the Western biomedical world should be aware of. Both types of knowledge lead to a similar scenario that this chapter started with, where patients either cannot get diagnosed or treated. What is hopeful for patients, contrary to the dilemma of the colonel, is there are specialists who can diagnose and treat HD patients. However, it is assumed by my informants that many healthcare professionals generally do not know about the status of the clinics where specialists work. These specialists may find themselves tip-toeing around how to make their presence known in their community without prompting a misleading scare of a HD epidemic. This presents a Catch 22 situation.

Advertising the Clinic Status

The 'status' I refer to is one of two types. One is that in which a clinic is a NHDP funded clinic, and therefore a physician is present who has been recognized by the program to handle HD cases and who subsequently can offer such services free of charge. This was the case with three of clinics in my study, one of which was located at the NHDP in Baton Rouge. Two, a clinic has a specialist or someone who has experience treating HD patients and likely has funding to help patients but is not funded by the NHDP. This was the case for my one non-NHDP funded clinic. Each clinic was strategic and careful in their approach to community outreach. Awareness of their status is critical for patients who need to be treated by those most informed about the

disease, especially when complications arise. Awareness is also critical because these clinics have funding that is specifically for the treatment of patients. When patients do not have insurance, as my informants stated about half of their patients do not, financial concerns can be a deterrent in seeking care (Derose et al. 2007; Chernew et al. 2005). The NHDP funding is possible because of the history of HD in the U.S. As one informant noted, the government took responsibility for these patients as a result of the imperialistic (my word) treatment of these patients (through forcible confinement and separation from their families) and therefore the USG is still providing funding and support for patients.

Each clinic has approached community awareness with different approaches. I am only aware of such activities at three of the four clinics. One of these is the NHDP and I discussed their awareness seminars in a past chapter. However, they have also recently begun to engage with immigration services in hopes to develop a system where information about their status can be distributed to incoming immigrants. This is especially important since 80% of cases in the U.S. are immigrants (Carus et al. 2001; WHO 2011). Additionally, the majority of immigrants today are coming from endemic areas such as Asia and Latin America (Loutan 2001). Another clinic has entered into their local community seeking out healthcare professionals who treat those most likely inflicted by the disease, immigrants from certain geographical regions, where HD is endemic, who settle in their community. A college student in this community did a special report on the clinic to make their status known. However, the clinic has been present in the community since the mid-20th century. Therefore, initial anxieties of the clinic have likely been relinquished because people in the community have been aware of the clinic existence for a long time (Dermatologist Informant 2012). The third clinic recently received funding. They are

currently developing processes for distributing information. One idea is to form a mailing list of healthcare professionals who may treat immigrants at-risk for HD. I have been invited to be part of this process. However, how to phrase the wording in the letter is one of the challenges the clinic faces. As is clear, not all healthcare professionals are aware of HD and when they are they may not understand it clearly. Therefore, sending letters to healthcare professionals could increase the chance patients could be treated in a discriminatory manner, as some of the patients in my informants' examples have. Again, a Catch 22.

Whose 'Knowledge' is this Anyway?

Many of my informants emphasized that it is becoming increasingly important for healthcare professionals to be aware of global health issues in our increasingly globalized world. Almost all of my informants had either specialized in knowledge of the disease process, or have worked extensively in infectious and tropical disease issues through their infectious disease and tropical medicine fellowships. This has, in my opinion and theirs, allowed them to be more aware of global health issues. I question, should medicine, by nature, be a medicine of global health, with the increasing transitional movement of people?

HD has found itself on the list of neglected tropical diseases (NTDs). Among these diseases you will also find Yaws, Schistosomiasis, Chagas, Dengue, and Human African trypanosomiasis (or sleeping sickness), just to name a few. These diseases are neglected simply, as one informant put it, because they are forgotten. However, these diseases are emerging as more people are exposed to them, either by traveling to of coming from an endemic area. With HD being a neglected tropical disease, that has mostly been absent from the US healthscape it

may be no wonder healthcare professionals do not have more training and awareness of this disease. The last major tropical disease outbreak in the U.S. occurred with yellow fever in 1878 (Gussow 1989). The U.S. reacted by implementing strategic quarantines and community hygiene regulations (Gussow 1989). In this case the disease was controlled through establishing an understanding of the mechanisms through which it is transmitted. However, there are many uncertainties about the "medical truths" (Dumit 2010:370) about HD (clinically or socially). The absence of such truths leads to metanarratives that are culturally unique as people try to explain and understand a disease even the specialists still struggle to understand. As one informant said, Gerhard Armauer Hansen might be embarrassed we still cannot figure out the disease a century after he discovered the bacillus. Subsequently this leads to "uneven flows of knowledge and contradictory versions of acceptability and legitimacy" (Dumit 2010:370).

It is not just about recognizing the disease at a clinical level; it is also about understanding the disease on a social level. There are real people who are influenced by these knowledge gaps that I propose causes problems for HD patients. Gussow (1989) suggests there is no other disease that has withstood time in terms of the deeply rooted stigma. Furthermore, Gussow (1989) suggests that for the stigma to persist, as it has, there has to be an assumed threat to the public. In the U.S. such a threat was once envisaged as the yellow peril where an assumed threat cumulatively lead to the establishment of the first colony in Hawaii to sequester Asian immigrants who might have had the disease. There has been a history since the first attempt to purposefully exclude immigrants to keep such threats on the margins of society. Douglas (1966:119) argues such margins are dangerous as they represent transitional states that are

"undefineable." All those in these transitional states are dangerous, because they themselves cannot be defined (Douglas 1966).

Transitional States of Knowledge

The relationship between patients and healthcare professionals are not closed-systems of information exchange as social and economic influences intrude on such interactions**.** While these macro-level forces influence perspectives, so do micro-level, or individual understandings. Anthropologists have questioned the power of ethnography to depict people as possessing a higher knowledge as an insider of a particular culture of interest. However, this higher knowledge is not void of personal subjectivities, and anthropologists constantly struggle with that. I question, can we simply tell healthcare professionals their subjective understandings of the disease are wrong and expect them to change? While my informants were critical of their fellow healthcare professionals, many felt that the stigma that encapsulates HD will never be eradicated. Due to this, medical professionals are placed in a realm of negotiations where they are expected to have biomedical understandings of disease, void of subjectivities. As anthropologist we ask healthcare professionals to recognize their subjectivities. I ask, can we ask that?

There are no absolute truths. One person's reality can become another's prison (Appadurai 1996). As healthcare professionals see more and more patients from varying backgrounds, they may be forced to adapt and subsequently change their perspectives. One informant even optimistically noted, the world is constantly changing, people are moving more and more, and it may just take some time to catch on. Regardless, these perspectives will remain partial, even as outside influences challenge these perspectives. Gussow (1989) questions

whether the stigma surrounding the disease is possible to change because the stigma may be too deeply rooted. Gussow (1989) also asks if the disease for which the U.S. confined affected individuals to leprosaria is the same disease we speak of now, or even if the HD of the leprosaria era is the same disease of the ancient religious texts.

Appadurai (1991) encourages his readers to deterritorialize their beliefs to welcome in a globalizing world, but to maintain a locally situated gaze. This gaze will never be pure. However, there are other ways of knowing. Appadurai (1991) may argue one way to know is to become more open and understanding of the global cultural flows, as they are influencing our daily lives in a way we may not even be aware. With this we must adapt, as the one physician has welcomed his patients to text message him and send him pictures of lesions as a way to check-in. However, I think the global cultural flows in the medical world are experiencing a lag effect. This speaks more widely to globalizing disease and illness, not just HD. However, unless the stigma surrounding the disease is more thoroughly investigated in a contemporary setting in the U.S., an optimistic future for HD patients is less likely. We are caught in a Catch-22, whereby we cannot break ourselves of a historically rooted stigma that we still cannot put our finger on and subsequently we will continue to tip-toe around how to approach the disease making the continuation of such stigmatizing attitudes ever more likely.

6 BREAKING FREE OF THE CATCH-22 PARADOX

> "The fact of the matter, is it [the stigma] is just not going away" (Physician Informant 2012).

I struggled immensely with figuring out how to proceed to my conclusions. I wanted to be able to offer something beyond social reform many medical anthropologists suggest applications for. I wanted to extend applications of this thesis beyond the ivory tower (Singer 1995). I turned to Singer (1995) who says there has to be a fundamental commitment to change. I questioned, who governs those fundamentals? Who can be trusted with the fundamentals? The fundamentals of the disease are that is a curable, mildly infectious disease. However questioning who governs those fundamentals did require a retrospective look into the history of the disease in the United States. The history is grim. The fact of the matter is simple, that stigma most likely is not going to go away.

My methodology allowed me to capture perspectives eight healthcare professionals have of HD patient experiences. Since my informants had varied years and types of experiences I asked my informants to draw on an accumulation of their experiences while discussing HD. Some informants offered more background on HD while others provided stories that enriched and supported the arguments they made about such experiences. While I was "studying-up" in interviewing professional healthcare providers, I did not encounter many of the problems that Nader (1972) suggests are inherent to such studies. However, one limitation is that I was unable spend much time in a clinical setting. Instead I sought out other opportunities; such as the L.E.A.P. online awareness and training program offered by the NHDP. Additionally, my research could have greatly benefited in a comparative approach if I was able to include patients. This

would have allowed my study to be more holistic by providing the other side, the patient, to the story. Since access to patients was limited by the clinic at which I started my research I instead focused solely on healthcare professionals' perspectives but drew heavily from literature discussing the patients' perspectives.

The biggest barrier patients encounter when trying to access treatment stems from the stigma surrounding the disease. The knowledge-gaps that exist among healthcare professionals is a serious debilitating force for patients, regardless of immigration status. Healthcare professionals with these knowledge gaps either do not know how to recognize and diagnose the disease, or if they do, they may have a distorted perception of HD as a highly contagious disease. These knowledge gaps have serious consequences for HD patients often leading to advancement of the disease. Such advancement can lead to desensitization which may lead to infection, if the patient is unaware of injuries and does not feel pain in the site of neuropathy. Such infections can lead to deformities that people often associate with HD thereby further inducing stigma. Additionally, healthcare professionals who are aware of the disease may treat patients as contagious objects in need of careful handling. This is apparent in my informants' stories of physicians and hospital administrators who clearly believed the disease was capable of causing a serious public health concern.

While my informants recognized that the stigma of HD is experienced by all patients, immigrants and U.S.-born citizens alike, they did clarify that additional challenges are experiences by immigrant patients. Such challenges are experienced within and outside the clinic. Immigrants who enter the U.S. workforce in a lower income bracket are typically more vulnerable to health disparities because of limited and restricted access to adequate healthcare re-

sources which are costly. These challenges do differ within and between people and cannot be generalized to all immigrants. However, my informants stated many of their patients are immigrants who do suffer from socioeconomic shortfalls and whose decision to seek treatment is often governed by costs. The healthscape becomes violent place to those who cannot afford basic services, let alone specialized services at the clinics within which many of these informed healthcare professionals practice.

While such challenges are often experienced outside of the clinic, within the clinics healthcare professionals work to alleviate these challenges by providing resources to their patients. All four clinics in this study have funding that can cover treatment costs as well as other costs such as transportation and sometimes meal expenses. While getting to the clinic is half the challenge for patients, many additional challenges exist within the clinic. Healthcare professionals struggle to make sure patients return. More informants emphasized that trust is key. Many informants work to build trust by providing time and availability. Others have dedicated themselves to a lifetime of learning about HD. Through this learning, and the experiences that accompany them, my informants shared many stories about how they adapt to patient explanatory models of health. However, the challenges patients face seem somewhat out of the hands of the healthcare professionals who treat them.

Global Awareness

HD is a NTD. The United Nations Millennium Development Goals (MDGs) for 2015 call for the eradication of NTD's is among them, but the focus on HD has essentially fallen off the radar here. Such initiatives have been fostered by non-profits, private sector and bilateral

groups that are working with countries to eliminate these diseases. However, everyone is aiming big and subsequently HD, whose prevalence falls short of other NTDs, has been doubly-neglected. Additionally, HD is not a killer disease like diarrheal illness, malaria, TB and HIV/AIDs. Many NTD's are not life-threatening though. Most are chronic infectious diseases that do occasionally result in disease complications. While such efforts have been crucial in the eradication of guinea worm (thanks mainly to efforts by The Carter Center), and elimination of cases of polio in India (2011) these past few years, globally, the continuance of HD is not being addressed. So where does this leave us?

National Awareness

At the national level I turn to the healthscape to set the stage. The nation used HD in the early 20th century as a catalyst to immigration policies and subsequently that model was also applied in the public health realm. As one informant put it, it seemed logical at the time to take those affected by an infectious disease and isolate them. However, as another informant put it, what is unfortunate is when the motivations behind such isolation are misinformed. The Marine Health Services survey in the early 20th century proved that HD was not a serious public health concern (Moran 2007). Additionally, scientists in Norway , upon the discovery of the leprosy bacillus by Gerhard Armaeur Hansen, biomedicalized the disease and managed to control the disease while treating patients in a humane way (Gussow 1989). However, the disease maintained its identity of a disease of "inferior" people in the U.S. (Gussow 1989; Moran 2007). Such people were viewed as dangerous or polluting in the U.S. As Douglas (1966:123) states "pollution is a source of danger." The U.S. reacted by enforcing a policy of exclusion by pushing pa-

tients with the disease into the margins of society in leprosaria where they could not contaminate the rest of the country. This policy, and others that purposefully exclude immigrants (whether they be law or policy), continue to enforce exclusion, both physical and symbolic. Additionally, the institution of the U.S. biomedical system has fallen short in serving those inflicted by the disease. However, Foucault (2010) would argue this is not an issue of who is in the right and who is in the wrong, but instead insists we evaluate the structures through which such power as knowledge is enforced. The social, economic and political relations that influence understanding of the disease are beyond the control of patients and even healthcare professionals. Subsequently they are subjected to a polity of exclusion that may result in poor health outcomes. This is where future research can be conducted. An evaluation of the structure of medicine and the selective teaching of certain topics needs to be evaluated as our world continues to globalize and is further influenced by global cultural flows.

Local Awareness

This leads me to the topic of local awareness. The NHDP as well as the other clinics in my study have focused their efforts locally. These efforts have been successful. These healthcare professionals have been able to reach healthcare professionals in each of their communities through community outreach and public awareness campaigns, despite challenges. As with every successful global health solution (Guinea worm eradication, oral rehydration solution, polio eradication etc.) each initiative starts locally and then is subsequently scaled up. As one informant started, our clinics deal with third world situations daily just by the nature of our patients and the challenges they face. While it may be difficult to understand such ‘third

world situations' in our first world country, they are a reality for many people who seek treatment within our healthcare system. The next step would be to document these community level successes, develop a protocol for which the system was successful and begin spreading it. No successful global health initiative has been accomplished any other way.

Patient-Healthcare Professional Interactions

Overall my informants expressed frustrations with the experiences their patients encounter within the U.S. healthscape. The lag effect of medical education not keeping up with the globalizing world certainly warrants a closer look from different angles. These angles would require a researcher to investigate such interactions with patients of different diseases with a more comparative analysis. I posit that research on other conditions may not capture positive interactions with understanding healthcare professionals with patients of other diseases. As many of many of my informants stated, there is just something about this disease. However, this research is groundbreaking because the findings are in a field that mostly posits healthcare professionals as naïve to patient circumstances.

Conclusion

There are many challenges patients face if they have HD. Some of these challenges may be due to immigrant status while other challenges are due to the stigma of the disease. My informants created model examples for how healthcare professionals understand and adapt to their patients' needs. However, knowledge gaps about HD are rampant within the healthcare profession in the U.S. leading to debilitating interactions patients may have with healthcare

professionals outside these clinics. Many successful programs have been implemented at the community level that have resulted in effective outreach to area physicians helping to reduce stigmatizing perceptions of the disease for patients. Such models need to be expanded by scaling-up, a typical method in global health that has proven significant in eradicating some disease and various health disparities. While many informants felt the stigma would never be eradicated because of how deeply embedded it is in many societies, other optimistically noted that it may just be a matter of time before the world catches on and frees HD patients of the debilitating effects of knowledge gaps.

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8 APPENDICES

Appendix A
Questions for Health Professionals

Interview questions: HD and Immigration to Georgia
PI: Cassandra White, Assistant Professor, Georgia State University
The questions below will be administered by the student PI Interviews will be audio-recorded unless that participant prefers not to have the interview taped.

Male/Female

What is your position at the clinic? How long have you been here?

What type of education and training have you had? Do you have a specialty focus? How many years have you been practicing medicine?

Why are you working in travel medicine? What training has been specific to this career?

What is a day like for you at the clinic?
Probe/Transition: Other than travel advisement, what else do you see patients for?

Do you see cases of neglected tropical diseases (NTD)? How often?

What are the most common NTD's seen at the clinic? What NTD's do you have the most experience treating?

How and where do patients often contract NTD's?

What is the demographic of the patients you see with a NTD(s) (e.g., age, sex, citizenship, socioeconomic standing)? Do you recognize any disparities within these different demographics?
Probe/Transition: How often at NTD patients immigrants? How do you account for this?

What have been your experiences treating immigrants with NTD's? Are there any barriers you notice immigrant patients have to overcome to acquire treatment (e.g., access to treatment, financial barriers, documentation status, stigma, cultural barriers)? Does the clinic provide medical interpreters?

What experience do you have treating HD? If none, what experiences from your training might you draw on to treat Hansen's?

What is the history of Hansen's treatment at the clinic?

What is the treatment procedure for Hansen's patients?

What type of training is required to treat Hansen's? Is the training primarily biomedical based or is there also a social/cultural component to training?

What social/cultural considerations do you take into account while treating Hansen's patients? Are there other considerations when patients are also immigrants?

What are the difficulties in diagnosing HD? What are people with HD commonly wrongfully diagnosed with?

How does delay in diagnosis affect patients? How often have you or do you expect to see patients wrongfully diagnose?

Will having a NHDP clinic in the area change the rate of occurrence of this delay? Is this effect something the clinic is interested in measuring?

What is the importance of receiving recognition from NHDP? Does this recognition change anything about treatment of Hansen's at the clinic?

In terms of the free treatment, are there requirements to receive free treatment? How much would treatment typically cost?

What role do area physicians have in referring Hansen's patients? How will area physicians know about NHDP recognition?

Given that many patients are currently not at this clinic for treatment, how will patients be recruited?

How do you account for there currently being no patients?

What are other diseases and illnesses are common for people with HD to be co-infected with? Do you/will you treat these in addition to Hansen's? Will the free treatment also encompass treatment of other diseases patients are co-infected with?

Are their common interactions with the MTD for Hansen's? What about with other drugs patients might take with co-infection?

Would you be willing to answer follow-up questions if I have any?