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Uma Doença Esquecida: A Falta de Conhecimento da Hanseníase no Brasil

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Abstract

Hansen's Disease is one of the world's most misunderstood and stigmatized illnesses. Its patients are often discriminated against, and marginalized from society. This study examines what role a fault in information regarding technical knowledge plays in perpetuating this prejudice. Data is based on interviews collected from patients, family members, and persons from the most affluent sections of society, all from the city of Ilhéus, Bahia, Brazil. In addition, medical professionals provide their input. This information is referenced against sociological theory and historical precedence, to examine the role society and government have played in formulating the situation today. The study concludes that while unawareness runs high in the municipality, the prejudice felt by patients was much lower than expected.

Introduction

“Ela é perigosa?” (“is it dangerous?”) asked the matriarch of the house. Sensing my confusion, she repeated, “Ela – a doença – é perigosa?” (“It – the disease – is it dangerous?”). This time I understood. She was asking if *hanseníase*, the disease she suffered from, was dangerous. I did my best to explain to her the symptoms and potential effects of the disease, while also emphasizing that *hanseníase* has a known cure. She seemed quite relieved, but I on the other hand, grew a little bit worried.

Hanseníase does not have to be dangerous. With proper attention and diligence, the disease can be cured in as few as six months. In addition, while under treatment, the disease is rendered non-contagious. But, without medical assistance, *hanseníase* can

cause nerve damage, leading to physical deformities, and it can be transmitted from one human to another.

Unfortunately, such knowledge is not widespread within the Brazilian population, or even within the relatively small group of individuals afflicted by Hansen's Disease itself. Instead, doubts, uncertainty, and misconceptions taint or confound the public perception of an already confusing illness. In addition, Hansen's Disease has been the victim of intense stigmatization – once again, the result of false impressions.

This study examines awareness levels and social contextualization of Hansen's Disease in the Brazilian municipality of Ilhéus, Bahia. The central idea hypothesizes that a fault in understanding perpetuates the disease's stigma, leading patients to experience high amounts of prejudice and discrimination. Based on interviews with patients, health professionals, and citizens at large, the goal is to create a better understanding of how individuals understand and perceive Hansen's Disease.

The project concludes that, while there are many faults in information about Hansen's Disease, this has not created an overwhelming stigmatization of the patient population. Paradoxically, the individuals most likely to feel discriminated are members of the upper class, but such discrimination is likely to come from members of the same socio-economic standing. In addition, if Hansen's Disease is to be overcome as a question of public health in Ilhéus, the municipality must take charge in distributing and explaining information about the illness.

These conclusions leave room for additional studies, specifically on the relationship between Hansen's Disease and leprosy, the situation within the wealthier

classes of Ilhéus, and the causal correlation between a fault of understanding and the prevalence levels of the disease.

Importance of Research

Hansen's Disease, also known as leprosy, continues to pose a major public health concern in many countries. Today, there exist effective treatment strategies and modern medicine allows the disease to be effectively controlled, but other barriers such as misdiagnosis, poorly trained professional, and a widespread stigma surrounding the disease have posed significant challenges to its control. Elimination of the myth of Hansen's Disease as an incurable, highly contagious, and debilitating disease has to change in order to encourage patients to seek treatment and diminish their discrimination from the community.

In 1991, the World Health Organization adopted an initiative to eradicate Hansen's disease worldwide by the year 2000, with eradication defined as a prevalence of less than one in ten thousand persons. The number of Hansen's Disease patients dropped from 5.2million in 1985 to just 286,000 at the end of 2004. There has been a twenty percent annual decrease in the number of cases detected globally for the past five years. While the campaign was a success on a global level, eleven countries failed to meet this goal by the intended date and nine countries have still not eradicated the disease. These nine countries account for over seventy-five percent of leprosy cases. Brazil, India, Mozambique, Nepal, and Madagascar are currently the principal focus of elimination work (WHO 2005). Efforts are now being directed at implementing effective public

health programs aimed at getting information to the poor people of endemic areas that are most likely to contract the disease and ensuring free treatment availability.

Many people think of Hansen's Disease as a very rare, almost extinct illness that does not plague those immediately around them. In the case of Brazil, however, this is a serious misconception. The main reasons that endemic countries struggle to control the disease stems from political and economic instability and a large, uninformed poor population that suffers from inadequate healthcare and a lack of hygiene. The World Health Organization openly declared:

“Poverty is both a cause and result of leprosy. A cause insofar as poor people are more prone to suffering from leprosy as they have weaker immune systems and live in close proximity to one another resulting in higher risk of contracting the disease. Leprosy also leads to poverty, as it is a leading cause of permanent disability in the world. The chronic symptoms often afflict individuals in their most productive stage of life, and impose a significant economic and social burden on their families and society at large” (WHO website).

As a public health issue, Hansen's Disease is considered “defeated” when the infection rates within a given country are at or below one case per 10,000 individuals. Worldwide, these goals have been met: almost all of the world's countries, especially the most developed nations, have long since achieved these standards set by the WHO. In the developing world, however, the disease remains endemic in a handful of countries. Today, Brazil is home to the world's second largest *hanseníase* population, behind only India. Even within the country's various regions, however, the prevalence rates are not equal: Brazil's southern states no longer consider Hansen's Disease a public health question, while the north and northeast regions maintain case totals well above the world average (Ministério de Saúde 2006, 7). But, no matter where the disease is found, Hansen's Disease tends to prey on society's poorest sectors. In such situations, poor

living conditions, low levels of education and inadequate medical services combine to provide the ideal breeding ground for the disease.

Historically, *hanseníase* has drawn a severe social stigma, often stemming from the disease's physical debilitating affects and its association with poverty. In many parts of the world, the illness is more commonly known as Leprosy, a disease the Bible cites as "impure" (Bíblia Sagrada, 125). Religious references and subsequent public views of *hanseníase* often label the illness as highly communicable and tainted. As a result, many patients of Hansen's Disease live on the margins of society, cast away from mainstream livelihoods.

Unfortunately, such perceptions are based on a fault of understanding, rather than scientific facts: while transmissible, almost 90% of the world's population has a natural immunity to the *Mycobacterium leprae*, and the disease ceases to be contagious once the patient begins treatment. Moreover, as the Brazilian propaganda goes, "*hanseníase tem cura*" – Hansen's Disease is curable, and the WHO provides Brazil with all the necessary medications free of charge. Genetics and quality of life, rather than moral standards, represent the major determinants of who is afflicted by Hansen's Disease and who is not.

Ignorance, therefore, is more often associated with Hansen's Disease than is acceptance. *Hanseníase* has never been a worldwide killer, and its presence in many locations is often denied, rather than explained. The historical tendency to isolate patients of Hansen's Disease has not only reinforced the social stigma, but it has perpetuated the general lack of awareness. Many people have no idea what Hansen's Disease is because they have never the opportunity to interact with one of its patients.

Justification

On a personal level, I was drawn to this question because I perceived Hansen's Disease to be an unnecessary burden on society. The disease's continued prevalence in Brazil, despite it having a known and provided cure, should serve as an immediate source of concern. Health is a human right, and the individual's access to such rights must be guaranteed. There is no reason that Hansen's Disease should continue afflict patients with its physical and psychological effects.

Academically, the persistence of Hansen's Disease also intrigues me. As a student of International Development, I am constantly searching for topics that relate to economic growth. Hansen's Disease, as a disease that has been wiped out in the first world, presents an interesting question. Its reappearance in Brazil, especially after much political focus and economic resources were redirected to the HIV/AIDS, is indicative of the country's status as a semi-developed nation. At some point, I would like to investigate the broader relationship between public health and development. By choosing a disease, therefore, that has distinct connections to a country's level of economic growth, I am hoping that this project will serve as the first step in that pursuit.

This paper investigates awareness levels and social contextualization of Hansen's Disease. With medication and treatment services available to all free of charge, I wondered there was an external factor affecting the persistence of *hanseníase*. More specifically, I wanted to assess how patients and other members of society understood the disease: could they explain what *hanseníase* is, how it is transmitted, or name its symptoms? Moreover, did they believe there was a stigma associated with the disease? At the same time, because Hansen's Disease is much more common amongst some of the

world's poorest individuals, socio-economic standing can also detrimentally affect perception. In other words, by associating the disease with the plight of poverty, richer individuals reinforce the standard that Hansen's Disease is a "dirty" illness, which strikes only those individuals without the means to maintain basic standards of hygiene.

In the course of developing these questions and researching the topic in academic literature, I started to form a number of assumptions. I honestly believed that all patients of Hansen's Disease were the victims of severe psychological trauma, stemming the stigma associated with the illness. In addition, I expected most other individuals to possess strong and definite opinions regarding the disease.

While I would not describe myself as prejudiced, I can openly admit that I had very little understanding of the disease before embarking on this project. I had never met a patient of Hansen's Disease, nor could have I provided an accurate portrayal of the disease's symptoms or modes of transmission. At certain points, my own misunderstandings forced me to reconsider the efficacy of my study: could I really hope to contextualize a disease that I did not understand? I resolved to learn as much about the illness as I could, prior to beginning the interview process. I was afraid patients would perceive my motives as insincere if I was unable to relate to the information they provided. Additionally, I did not want patients to feel like rat in a laboratory experiment. I had a personal goal of remaining calm and collected in front of all participants, regardless of what challenges arose.

In the end, completing this project taught me a lot more about myself than I could have ever expected. Of course, like I set to do, I also learned a lot about the disease, its manifestations, and challenges confronting its defeat. But what I also discovered is that

meaningful research extends well beyond printed figures or verbose essays. The real challenge is forcing yourself to become immersed in a question, allowing for interpretations from various perspectives. That is to say, research of this sort not only teaches you to question your first intuition, but in addition, to continue questioning every subsequent instinct. Only at this point, when you have thoroughly exhausted all possible explanations, can you then rest assured that your initial hunch was probably correct. But without this exercise in critical thinking, you have to doubt your own dedication to the purpose of the study.

Methodology

The study relies heavily on data collected through fieldwork conducted throughout the city of Ilhéus. I worked primarily at SESAB (part of the state government and the only local health post with treatment for Hansen's Disease), interviewing patients of Hansen's Disease, other visitors, and medical professionals to gain insight into their understanding of the illness. Other interviews were conducted outside of the medical centers, generally with members of the "upper class" – a term that indicates that segment of society that often has professional jobs, owns their own homes, and enjoys a certain degree of luxury. I visited homes of patients and also spoke with family members to gauge how inter-domiciliary contact could affect an individual's understanding.

Responses to these questions were then compared against the respondent's education level. Because Hansen's Disease suffers from little public exposure, education levels play an important role in determining how an individual comes to learn about the illness. Moreover, education levels can be indicative of one's socio-economic standing.

People with the ability to afford continued schooling may have more opportunities to expand their knowledge on a wide range of issues.

Interviews were based on two different questionnaires: one used for patients, a separate one used for everyone else (see Annex). The questions remained standard, regardless of the participant's education level or perceived socio-economic status. The goal was to determine how these two variables would affect an individual's responses.

The majority of my observation was informal. There are many factors – including stigmas and physical deformities – that can only be understood by those individuals who are afflicted with the disease. My goal was to illicit comments from the participants that would help me gauge the level of awareness in addition to revealing any prejudices or discrimination present throughout society.

I also met with several health professionals. Generally, these encounters were recorded to ensure accuracy, while the less formal interviews with patients and others were only documented in writing. My questions for the doctors and nurses were twofold: first, I wanted to know what role they served in helping to educate patients about the disease. Second, I presented them with any findings I had at that point, requesting that they reflect and attempt to interpret the results.

Finally, this project required some quantitative research as well. I worked with the local Department of Epidemiological Vigilance to collect statistical information on the disease's prevalence and its change over time. My aim was to assess how the worldwide goal of reducing the burden of Hansen's Disease was playing out on the municipal level of Brazil.

Because this study focused on social contextualization of the disease, it would have been helpful to include patient perspectives from a broader range of socio-economic classes. In research about prevalence, such a move would not be recommended because it would distort the reality of the disease. But in this instance, where focus shifted to perceptions, I would have liked the opportunity to include a broader range of patient perspectives.

Location

Ilhéus, in the state of Bahia, is home to more than 220,000 residents. Once famous for its cacao plantations, the export of the crop has decreased dramatically over the past few decades. Nonetheless, its influence can still be seen in society: most of the middle class families in Ilhéus either formerly owned, or continue to operate, their own farms. The ownership of large pieces of land, in fact, often serves as a status symbol. For many families, the farm has long since ceased to provide the household's principal income, but the decision to retain the deed is directly related to social implications of being a landowner. In many cases, such a distinction is associated with a family's history, and it bestows upon them a sense of privilege and honor.

Despite boasting a population of nearly a quarter of a million people, most residents consider Ilhéus to be a small, interior town. In comparison with the two nearest cities – Salvador to the north and Vitória to the south – such an assessment is warranted, although Ilhéus is hardly a small village. Ilhéus has both an airport (with daily flights to and from Salvador and São Paulo) and an active port. The city still exports a number of agricultural goods, and its port also serves as a docking point for mid-sized tourist

cruises. Crime rates are lower in Ilhéus than in most other larger metropolises, although like any city, certain neighborhoods are notorious for being more dangerous than others.

Ilhéus is divided into the city and its periphery. The city consists mainly of commercial centers and middle class neighborhoods, while the periphery is predominantly lower class. As is the case in many Brazilian cities, the gap between rich and poor is striking in its effects on living conditions and education opportunities. While wealthier families enjoy more spacious homes and easier access to schools, the poorer families in Ilhéus live in crowded surroundings and find it much more difficult to obtain a formal education. In many instances, the periphery is located in some of the city's least desirable locations. Frequently, these communities are far removed from the city's commercial heart, limiting their access to basic necessities (such as supermarkets) and the city port.

Socio-economic status also dictates one's means of transportation around Ilhéus. The city provides a bus system, where one ride between any two points costs R\$1.45, but most families living in the city's center owned their own cars. Those individuals living on the periphery, however, and thus requiring farther travel to reach the city center, almost exclusively used public transportation or, when they could not afford the ticket, relied on their own two feet. The paradox is clear: those with the farthest to travel, have the fewest resources to make the trip.

This dilemma also has implications for patients of Hansen's Disease. SESAB, the only health center in Ilhéus with the resources to treat the illness, is located near the commercial center, far removed from the homes of the majority of the patients. As opposed to the Family Health Program, whose posts are located in or near the

neighborhoods they serve, SESAB is designed to serve particular diseases for the municipality as a whole. More specifically, SESAB is the city's main resource for the treatment of AIDS, Tuberculosis and Hansen's Disease. Within the building, patients can receive medications, clinical assistance, and related vaccinations for these three main illnesses.

The treatment wing for Hansen's Disease shared its space with the medical team for Tuberculosis. In this part of the building, there was a joint waiting room, two separate consultation spaces used by doctors, and another room where nurses provided assistance and handed out medications. The walls were covered with posters containing useful information on how to identify and treat both Hansen's Disease as well as TB. In the waiting room, patients sat on wooden benches until their name was called. TB patients were generally met in one room, where the resident physician provided check-ups and dealt out prescriptions. Likewise, in the second consultation room, a dermatologist and an occupational therapist worked with patients of Hansen's Disease.

The Disease

Leprosy is caused by infection with *Mycobacterium leprae*. These bacteria infect macrophages and Schwann cells, leading to skin lesions and peripheral nerve degeneration. If left untreated, permanent skin and nerve damage can result along with deterioration in the limbs and eyes. Contrary to popular thought, leprosy is not highly communicable. Prolonged contact with patients who have open lesions and are not in treatment is generally required for infection. The incubation period of the bacterium is

generally about five to seven years, although symptoms can take as long as twenty years after the initial infection to appear (WHO 2005).

Hansen's Disease in Brazil – A Mixed Record

The earliest references to Hansen's Disease in Brazil come from the city of Rio de Janeiro, near the onset of the seventeenth century. Cases were continuously registered during the following decades, leading the colonial government to seek help from the Portuguese crown. No official steps were taken, however, until nearly two centuries afterwards. Not surprisingly, when compared with how Hansen's Disease was dealt with in Europe during earlier time periods, the Portuguese government instructed its colonial officers to segregate individuals afflicted by the disease. Patients were subsequently isolated in leprosariums (Queiroz and Puntel, 1997).

In his work, Lana (1992, p. 122) points out that colonial Brazil lacked the political motivation and willpower to effectively tackle the question of Hansen's Disease:

“The historical analysis shows us that during the period before the Proclamation of the Republic, Hansen's Disease was not an object of state intervention or health practices. There were asylums, maintained through public charity, where the patients remained isolated and pushed aside from society.”

Only since the inception of the Brazilian Republic in 1889, therefore, has Hansen's Disease been recognized as a public health problem. But even at this point, patients were still resigned to specific colonies, designed to reduce their contact with society as a whole. The logic behind this campaign argued that the confinement of individual carriers of infectious diseases would inevitably bring about the eradication of

the various maladies. Little consideration was given to the actual causes of the diseases or their various modes of transmission (Queiroz and Puntel, 1997).

The government figure at the time responsible for this style of treatment was Oswaldo Cruz, Brazil's first minister of health. Cruz pursued hygienic standards through authoritarian tactics, a strategy that actually resulted in violent protest when the government attempted to enforce obligatory vaccination against yellow fever in 1907. By 1920, with the creation of the National Department of Public Health, several additional measures were instituted to combat Hansen's Disease: compulsory registrations, restrictions on employment opportunities and abilities to appear in public, disinfection of personal belongings, as well as immediate isolation of all children born to patients of Hansen's Disease (Queiroz and Puntel, 1997).

Isolation would continue to be the primary treatment method for the next several decades, even though its effectiveness was limited and its use perpetuated the disease's stigma. Even in the second half of the twentieth century, following the creation of the National Campaign to Control Hansen's Disease and the discovery of the antibiotic group sulfones, many patients continued to live in colonies.

As time progressed, however, most of these colonies altered their basic structure. In many instances, the centers took on qualities of clinical hospitals, where they were equipped with dermatologists and medications capable of treating the disease. The centers were commonly known as hospital-colonies, a title that emphasizes the dual focus on treatment and isolation. For patients, these hospital-colonies were a welcomed change. In his book, Antonio Borges recounts his new life in the hospital-colony of Águas Claras, in Salvador:

Here you breathe fresh air, you hear the birds and you see the streetlamps light up from the tiny villa (...). Our food is of the highest quality (...). I've never had so many blood tests but I finally believe in their purpose (...). Here, everything is so pretty that even on rainy days we see rainbows over the forests, so green that it symbolizes our hopes (Borges, 2000, p.49)

At the same time, while patients were finally receiving the necessary medical attention, they nonetheless remained isolated from society. In many instances, even when the treatment proved effective at curing the patient, the psychological effects of continued segregation were too much for the individual to overcome. As a result, many patients decided to remain in the hospital-colonies, convinced they were still sick, rather than re-integrate themselves into a prejudice-ridden society (Bloombaum).

In the 1970s, the configuration was altered once more with the restructuring of the ministry of health. The new Brazilian health system adopted measures to encourage preventive and community health programs, which would gradually alter the treatment of Hansen's Disease. Nonetheless, hospital-colonies were still the most common form of treatment, even though the World Health Organization started recommending pure ambulatory strategies starting the 1960s. Included in this scheme was new emphasis on raising awareness of the disease and breaking down long-held perceptions. Brazil took an important step by officially substituting the term Hansen's Disease, or *hanseníase*, in lieu of Leprosy, in an attempt to diminish public prejudices concerning the disease. In addition, with the passage of Decree No. 76.068/75, the government consolidated its *hanseníase* programs under the sub-ministry of National Division of Sanitary Dermatology and National Campaign Against Hansen's Disease. This consolidation,

moreover, represented a new beginning in Brazil health politics, in which treatment and prevention of the disease received equal attention.

In 1991, following the creation of the *Sistema Único de Saúde* (SUS), Brazil accepted WHO recommendations and began to use a multi-drug therapy (MDT) scheme in the treatment of Hansen's Disease. Despite this measure and Brazil's promise to eradicate the disease by 2000, *hanseníase* persists as a public health problem. The process of decentralization is still incomplete, with health services for Hansen's Disease not available at all health posts (Interview). The WHO several goals for all country's still combating the disease:

- Expanding MDT services to all health units
- Assuring all that new and existing cases receive access to MDT schemes
- Encouraging patients to take their medication regularly
- Promoting awareness about Hansen's Disease in the community so that individuals, who potentially have the disease, will take the initiative to seek medical advice
- Establishing goals for Hansen's Disease-related activities
- Maintaining adequate records to monitor all progress (WHO 1995)

Review of Literature

The misconceptions surrounding leprosy are deeply rooted in its changing nature. The current reality of the disease is so different from what it was in the past that many countries have officially changed its name from leprosy to Hansen's disease in order to keep people from transposing their ideas about leprosy to the illness that now exists.

Still, most people fail to realize that Hansen's disease and leprosy are different designations of the same illness, that it can now be easily controlled and cured, and that it carries a relatively small risk of infection. Stigma continues on the basis of these false ideas and other dangerous assumptions.

It is essential to look at the historical context of the illness to understand how the prejudice and misconceptions surrounding Hansen's disease became so engrained in international culture. Leprosy is one of the earliest recorded diseases, with early references dating to about 600 B.C. It was immensely more common in the past than it is today. Estimates suggest that there were approximately nineteen thousand lepers in Europe in the thirteenth century. Nevertheless, Hansen's Disease had nearly disappeared from continental Europe by 1870 due to "the amelioration of socio-economic conditions experienced by the European people during the Modern and Contemporary Ages" (Ministério da Saúde, 16). The term "leprosy" that caused so much fear and panic in past centuries was a broad term, used to describe a multitude of skin deformities that are now distinguishable from one another (Gussow and Tracy, Institutionalization 698). While some conditions that were labeled leprosy were probably minor and not contagious, others were undoubtedly much more extreme and contributed to the intense fear factor.

Primitive medicine did not understand the bacterial cause of Hansen's Disease, nor did they have a treatment for it. With such conceptual and medical limitations, society formed its own assessments of the disease, leading to the creation of the misconceptions and fears now associated with the disease. The Catholic Church, which viewed leprosy to be some sort of divine punishment, established the first code concerning the way lepers were to be treated in society. This code demanded their

complete isolation, and lepers were forced to caution others of their presence by wearing clothes that identified them as lepers and yelling “Impure! Impure!” (Ministério da Saúde 1989, 16). Unfortunately, with little knowledge on the disease’s cause, isolation was one of the most effective means to prevent its proliferation, although such measures were often taken to the extreme.

The misconceptions surrounding Hansen’s Disease influence the reactions of those diagnosed with the illness. Newly-diagnosed Hansen’s Disease patients maintain the same pre-established ideas about the “myth of leprosy” as the rest of society, and they often transpose those ideas to their condition. Many of these patients anticipate that their disease, in line with some of the most widespread misconceptions, will be painful and incurable. Sometimes, patients are not even aware that the disease has an effective treatment. (Gussow and Tracy Status, Ideology, and Adaptation 318). Instead, patients expect to be marginalized, a fact that greatly influences their social interactions. In cases of such negative reactions, contracting Hansen’s Disease becomes the center of the patients’ lives.

One author (Goffman 1986) describes this phenomenon quite extensively in his work where he describes stigma as an attribute that makes one different from others in a less desirable way. As a result, the stigmatized person is thought of as bad, dangerous, or weak, and thereby reduced in our minds from a whole person to a tainted and discounted one.

Not everyone, however, views *hanseníase* with such morbidity. In a study performed by Queiroz and Carrasco, all of the middle class respondents interviewed saw Hansen’s disease as something very negative. However, forty-six percent of the lower

class respondents viewed their condition with relative indifference (487). In general, the study shows that more educated upper class actually knows only as much, or perhaps less, about Hansen's disease than people with little or no schooling. Possible explanations for this include that most awareness campaigns have been aimed at the more endemic lower class as well as the fact that the upper class is a lot less likely to recognize the threat as pertinent to their reality (Gussow and Tracy, Institutionalization 696). In other words, the association between Hansen's Disease and poverty influences wealthier individuals to avoid taking the time to understand the illness because they presume they are not at risk.

Paradoxically, however, limited knowledge about the disease can actually help encourage more effective health practices. Many patients who are diagnosed with Hansen's Disease do not realize that it is the same illness as leprosy. Fifty percent of a Brazilian patient group interviewed did not consider the two to be the same disease or thought they represented different stages of the same illness. One woman interviewed confessed, "I don't know what leprosy is, I've heard it's a very bad disease... Thank God I've never seen that disease. What I have is Hansen's disease" (Queiroz and Carrasco 484). In the video *Os Desafios da Cura* (The Challenges of the Cure), the comment of one patient being interviewed presented a startling reality. In the film, after visiting the doctor a patient calls her son and informs him she has been diagnosed with Hansen's Disease. When her son asked her whether she knew what Hansen's disease was, she responded with a correct clinical description: "Yes, it is those spots on your skin where you don't have any sensitivity." To this her son responded, "Mom, Hansen's disease is leprosy." At that moment the woman remembered going into panic. The symptoms and

treatment of the disease are not what frighten patients; it is the social implications of being a leper. As a result, by remaining unaware of Hansen's Disease relation to leprosy, some patients might actually be more inclined to come forward about their condition.

Regardless of the reaction to their diagnosis, patients immediately adopt a sick role and strategy for coping with the illness process. Haber and Smith define disability as "the pattern of behavior emergent from incapacity – the loss of ability to perform expected role activities because of a chronic physical or mental impairment" (88). In the case of Hansen's disease, only progressed cases exhibit physical disability, but all patients experience the mental consequences arising from the psycho-social implications of being a "leper". Disability usually leads to sick roles that are adaptive responses to the biological limitations of the illness, but patients suffering from highly stigmatized diseases may develop an adaptive sick role as a measure to cope with social pressures exerted by the outside society.

Nancy Waxler argue that "Lepers learn how to be lepers from the beliefs and expectations their society has for them. In every society the sick person is socialized to take a role the society expects" (154). Those who adopt the traditional sick role assigned to them by the rest of society voluntarily withdraw themselves, often leaving their jobs and families. These patients are aware of the common ideas surrounding their disease. Because new patients hold the same images as others do about lepers, they have to cope with a great deal of self-stigma, as well as the stigma others have towards them. Self-ostracism is therefore a way to avoid rejection (Bloombaum, 20).

Self-withdrawal reflects feelings of social inadequacy. "A socially inadequate person may properly be defined as one who, by his own purpose, initiative, and efforts,

chronically is unable to maintain himself as a self-supporting and useful member of the organized society in which he finds himself” (Laughlin 69). People with Hansen’s Disease allow themselves to feel socially inadequate because they cannot withstand the stigma and fear that is directed towards them. A traditional view of a leper would qualify them as part of a group called “The Seven Devils,” of which the deformed, disorderly and dirty are also a part of (Laughlin 55). Consequently, there is a lot of voluntary confinement among the leper community. They are often unable to re-socialize even after being cured because the feeling of social inadequacy has become so engrained in their own view of their identity (Bloombaum and Gugelyk 17).

The sick role just discussed implies an open awareness context. The neglecting of social obligations leads to such dramatic modifications that the patient cannot maintain the secrecy of their condition. In an open awareness context, each person is aware of the other’s identity and their own identity as viewed by the other. More Hansen’s Disease patients, however, choose to maintain a closed awareness context, in which one individual does not know the other’s identity (Glaser and Strauss 670). The majority of people with Hansen’s disease in Brazil choose not to tell others about their condition because they want to be treated normally (Queiroz and Carrasco 485). The fear of being discovered governs most of their social interactions (Glaser and Strauss 670). A potentially dangerous outcome of this behavior is that many patients decide to not take the required medications for fear that others might see them. They find it easiest to protect themselves by maintaining their view of society’s ignorance regarding the disease.

Neither of these two sick roles play a part in decreasing the stigma or misconceptions associated with Hansen's Disease. Patients fail to challenge the inaccurate views society holds of the illness and the misconceptions persist. There does exist a sick role, on the other hand, that allows patients to do just that. Patients who have a better understanding of their disease are much less likely to accept the unjust role society tries to subject them. Career patients take upon the role of educators and confront the public with real facts. (Gussow and Tracy, Status, Ideology, and Adaptation 322). When people, who society has traditionally viewed as lepers, and treated with all the accompanying stigma, reject that role and demand to be treated as capable of functioning within society, so too do those around them develop a better understanding of the disease. Patients can convincingly promote their point of view because they understand the ideas held by their audience, and as patients they are thought to be very knowledgeable about the subject. Still, many career patients are faced with an emotionally difficult role conflict. While they are usually accepted in their role as educators, they are not necessarily socially accepted (323). It is therefore necessary to have a lot of commitment to maintaining this position and put oneself in a vulnerable position. Career patients, nonetheless, have great power to inform the general population and break down the debilitating stigma.

In order for efforts intended to decrease stigma to succeed, society must first be sensitized to the issue and make their actions permissible. Unpredictable behavior can be perceived as an intentional violation of societal norms, at which point undesirable behavior will be punished (Haber and Smith, 90). "Control agents reward conformity to the constructive norms and discourage behavior which violates these norms" (93).

Patients, therefore, cannot deviate from standard norms of behavior before society has a firmer grasp on their purpose. Without this understanding, in fact, patients might even experience further discrimination: their actions would be perceived as radical, and their message would be lost.

All of the generalizations and false ideas discussed above are reflected in peoples' attitudes towards Hansen's Disease. The end result is misunderstanding, and ultimately, stigmatization. Education and awareness, therefore, must be recognized as key factors in ameliorating the stigma, and consequently, aid in bringing an end to the disease.

Education can take many different forms, and there is a need to reach all sectors of society. Patients deserve education about the reality of their disease so they can understand how to alter their own behavior, national governments of endemic countries can launch information campaigns, and healthcare professionals must continue to better understand the illnesses they are treating.

Widespread information campaigns can be very effective in reaching the endemic communities, but only if the health professionals that organize them are sensitive to important cultural constructs of the Brazilian poor. For example, there is a common perception that Hansen's Disease is the result of harboring negative emotions, and that one cannot be cured so long as those emotions persist (Queiroz and Carrasco 482). There exists an "inadequate translation of public health knowledge into effective action across the social and cultural boundaries that separate those who have specific preventive and curable capacities and resources from those who may need them" (Hahn 5). This is directly related to the larger issue of culturally based perceptions and worldview. In order for public health workers to be able to act effectively, convincing the patients of the need

to take the medicine on a regular basis and otherwise effectively communicating with them, such healthcare officials have to understand the differences between their own culture and that of the community they are trying to reach. In order to do this, health workers must “know the social organization and values of the other culture” and take the “moral step of respecting, attending to, and addressing local perceptions, interests, and ways of life” (Hahn 8).

Medical Perspective on the Situation in Ilhéus

Currently, there are twenty-four patients receiving treatment for Hansen’s Disease at SESAB in Ilhéus. This total reflects a combination of new cases discovered this year, patients undergoing extended treatment due to the advanced nature of their condition, and patients who have stopped treatment in the past and are now beginning the process again. In 2005, fifteen new cases of Hansen’s Disease were reported in the municipality, matching the lowest detection rate in five years. In a city of 220,000 residents, fifteen cases equates to a detection rate of 0.58% (See Annex, Chart 1).

More than likely, however, these numbers are not indicative of the actual size of the endemic. In examining the ratio between cases of paucibacilar and multibacilar forms of Hansen’s Disease discovered in 2005, statistical data shows that multibacilar (the more advanced form of the disease) was twice as common. This trend corresponds with the data collected from the previous four years as well (See Annex, Chart 2). Because it requires several years for the paucibacilar form of Hansen’s Disease to reach advanced stages, a higher prevalence of multibacilar Hansen’s Disease indicates that a majority of the patients contracted the disease well before they were diagnosed. As a result, chances

are high that these patients also transmitted the disease to other individuals, who likewise will remain unaware of their condition for some time. Moreover, of the twenty four patients undergoing treatment, two were under the age of fifteen years old. Because the disease is only transmitted after extended exposure between an infected person and another individual, cases in children are especially worrisome.

Medical professionals in Ilhéus also seem concerned that the prevalence of the disease extends well beyond the printed figures. Dr. Sergio, the resident dermatologist at SESAB, did not flinch in his response when asked about the possibility that official data does not reflect reality: “Without a doubt,” he stated, “there are many, many non-diagnosed cases [of Hansen’s Disease].” In his opinion, this discrepancy stemmed from an awareness fault amongst Brazilian citizens. Dr. Sergio estimated that only 10% of patients of Hansen’s Disease arrive at SESAB already possessing some understanding of the illness, its causes, and its repercussions. The rest of the populace, he asserts, remain unaware, victims of an ineffective public health campaign (Interview, November 22, 2006).

Ana Maria Fontes, a registered nurse and professor at the nearby State University of Santa Clara, offers a slightly different opinion. Many individuals, she believes, purposefully resist diagnosis, often for a range of reasons. “[Individuals] are afraid to be diagnosed. They know it could be Hansen’s Disease because they have seen the propaganda.” But rather than seek medical assistance, individuals hide their condition in fear of confronting the social implications of contracting Hansen’s Disease. Ironically, as their situation worsens and the disease takes its toll on their nervous system, individuals

grow increasingly hesitant to seek a diagnosis, knowing that they now have the physical incapacitation commonly associated with the disease (Interview, November 22, 2006).

The low detection rate also has connections to the socio-economic profiles of patients. “In Brazil,” argues Juliana Pereira, a nurse at SESAB, “the epidemiology of Hansen’s Disease is characterized by low socio-economic conditions.” At the same, she points out, individuals living in poverty have little or no access to sources of information regarding the disease, including television, radio, and the internet. As a result, those individuals at the greatest risk are also the least informed (Interview, November 16, 2006).

The lack of awareness amongst poor citizens also has implications for the social contextualization of the disease. Some of these individuals are so uninformed that they do not associate Hansen’s Disease with leprosy. As Vitoria Luzia de Azevedo, another nurse at SESAB, points out, “none of our patients make connections with the social aspects of the disease. They have never heard of the disease, so they are not aware of the stigma.” (Interview, November 16, 2006). As Dr. Sergio points out, however, “patients may not perceive that the stigma exists, but it’s there” (Interview, November 22, 2006).

The causes for low levels of understanding amongst poorer citizens can actually be traced back to the medical professionals themselves. In Brazil, only public services provide treatment for Hansen’s Disease, reflecting the prevalence of the disease amongst the poor masses, rather than within the small portion of citizens who pay for private care. Many health professionals, however, are not attracted to public health concerns. Generally, doctors and nurses working in public health receive lower salaries and endure less comfortable conditions than their peers in the private sector. Medical professionals

sufficiently trained to diagnose and prescribe treatment for Hansen's Disease, therefore, are in short supply. In the words of Dr. Sergio, "there is an equal lack of information amongst patients and doctors" (Interview, November 22, 2006). Even when professionals possess adequate information, however, they are not necessarily effective in portraying the facts to the patients. According to Ana Maria Fontes, the nurse from UESC, "medical professionals use language that patients cannot access." The end result is such that "information is not successfully portrayed because it is presented in a manner that is completely out of synch with the social context of the patient." In other words, doctors tend to simply make a diagnosis and prescribe a treatment, without taking the time to effectively explain their decisions in a manner the patient can relate to. Patients, for their part, are often wary about seeking clarification. Ana Maria Fontes explains, "there exists a power-based relationship between the medical technician and the patient. As a result, patients do not feel comfortable expressing their doubt because they feel the ultimate opinions lies with the professional" (Interview, November 22, 2006).

Within wealthier social groups, individuals tend to be more aware about the disease, but their social standing affects their perception. Awareness, in this instance, does not necessarily imply understanding. Juliana Pereira argues that "the stigmatization takes place when people are capable of making the connection between Hansen's Disease and leprosy." Members of wealthier social classes have had increased exposure to the malady, whether it be through public information campaigns or through their extended schooling. As a result, such individuals are more likely to draw the connection between Hansen's Disease and leprosy. Juliana continues on to say "members of the upper class lead more public lives, which exacerbates their fear of the disease. They are afraid it will

affect their standing within society” (Interview, November 16, 2006). Ana Maria Fonte agrees, asserting that “the higher the social class, the worse the prejudices become” (Interview November 22, 2006).

Talking with Patients

There were very noticeable differences in the comfort and candor between patients when speaking about Hansen’s Disease. Patients who had little information or understanding were also much more inclined to act reserved, using short sentences or simple one-word answers. Some of the participants actually addressed me as “sir,” a seemingly unnecessary move when considering that the youngest patient was still six years my elder. These tendencies also corresponded with education levels: the more schooling an individual possessed, the more at comfort they seemed during the interview. The only two patients to possess college educations were also the most forthcoming and engaging of the participants. Their physical mannerisms demonstrated a heightened sense of awareness and an unabashed spirit.

At the very beginning of each interview, patients were asked to name their disease. Surprisingly, more than one half (nearly 60%) of the patients either failed to label their condition as Hansen’s Disease, or struggled to correctly pronounce the name, demonstrating a lack of familiarity with the diagnosis and the disease itself. In Brazil, the decision to officially change the name from leprosy to Hansen’s Disease was intended to reduce the stigma associated with the illness. Many patients demonstrated, however, that the use of the term “hanseníase” actually created more confusion than clarity. As one patient explained,

“[the doctors] use this name for my disease, but I didn’t recognize the word. I have never heard anybody else use it before, and I still never hear anybody use it today. There are a lot of words that the doctors use and that I never understand, but [“hanseníase] is the most common” (Interview I2, November 21, 2006).

For the patients who were able to identify their disease, this question seemed rudimentary and unnecessary. As one patient correctly pointed out, SESAB, the waiting room, and even the consultation room being used for the interview all contained posters advertising the name of the disease. “Even if I forgot,” he pointed out, “all I would have to do is look around” (Interview I1, November 25, 2006). Moreover, of the patients who correctly named the disease, all of them had at least eight years of schooling. Included in this group were the only two patients with a college level education. One of these patients, who simply responded “Of course – Hansen’s Disease,” also commented on the fact that, despite the name change, she had always known that Hansen’s Disease and leprosy were the same illness (Interview I16, November 29, 2006).

In the second question, patients were asked to reflect upon their awareness levels prior to receiving treatment. Out of the entire group, only two respondents (or about 17%) replied that they had even heard of Hansen’s Disease prior to their diagnosis. The overwhelming majority admitted to having never even heard of the disease, let alone possessing any knowledge on its clinical characteristics. Dr. Sergio Carvalho, the resident dermatologist at SESAB, actually predicted this situation: “Only a very small minority – maybe 10% or so – arrive at the medical post demonstrating some level of awareness.” The rest, he believed, were diagnosed with a disease that they had never heard of (Interview, November 22, 2006).

The two patients who responded affirmatively to the second question had varying sources of information. The first participant, who also had a college education,

remembered seeing a television advertisement that included persons afflicted by Hansen's Disease enjoying themselves on a beach. As the patient recalled, the message of the advertisement focused on providing basic information, including some of the disease's symptoms, as well as where to go for treatment (Interview I16, November 29, 2006). On the other hand, the second patient who said she had heard of Hansen's Disease prior to her diagnosis, cited her mother's own battle with the illness as the source of information (Interview I17, November 29, 2006).

Patients displayed a mixed record on describing the clinical attributes of Hansen's Disease. First, the participants were asked if they could name and/or describe any of the symptoms of the illness. An even quarter (25%) immediately responded that they had no idea whatsoever, which already demonstrates a startling fault in information. Only a small portion (around 17%) provided an incorrect answer, and in all of these instances, the patients actually identified symptoms associated with a reaction to their medication. Moreover, these specific patients seemed to be guessing.

"I often have a bad fever, so that must be a symptom. I did not use to get fevers so frequently, and I think it is because of the disease I have now. I am pretty sure that this is a symptom, and I do not think I have any others." (Interview I2, November 20, 2006).

A total of 58% of the patients correctly identified that spots on the skin can be a symptom, but of that percentage, only slightly over half associated the marks with a loss in sensation. In fact, one quarter of the original 58% believe that pain, rather than sensory loss, is associated with the spots on the skin. Only one patient correctly pointed out that Hansen's Disease has a wide range of clinical manifestations, of which spots and loss of sensation are the most common. She further pointed out that the hands and feet are where spots are most likely to occur (Interview I16, November 29, 2006) One third

(33%) of the patients mentioned physical deformities as a symptom. While peripheral nerve damage can be caused by Hansen's Disease, deformities are not considered a symptom.

Within the participant group, there was very little awareness as to how Hansen's Disease is transmitted. Only 25% of the patients correctly identified the bacillus's primary mode of transmission through respiratory tracts, although none of these patients highlighted that transmission only occurs after prolonged exposure to an already infected individual. Several of the patients actually used the expression "through the air" to explain their answer, a worrisome response because it implies a relative easy mode of transmission.

Another 25% of the patients were unaware, prior to starting treatment, that Brazil offered free medication and consultations for their disease. This confusion, however, seemed to reflect a more general lack of understanding regarding the treatment process rather than the politics of the Brazilian health system. As one patient explained,

"I knew that I could come to the health post to receive help, but I had no idea that they would already have a cure. I thought it was going to be a really complicated process, but the doctors told me that they already had the medicine and that I should start the treatment as soon as I could" (Interview I11, November 23, 2006).

Regardless of how much, or how little, a patient knew about Hansen's Disease, consultations with medical professionals represented the primary source of information. An entire 100% of the patients admitted to having been advised by doctors and nurses regarding important information about the disease. As has already been demonstrated in this paper, however, many patients fail to absorb these facts. In one interview, conducted at the house of the patient, I was joined by Dr. Giselle Holliday, an occupational therapist at SESAB. Dr. Holliday had decided to visit the patient's home because she was

concerned by the possibility that other members of the family had already been infected by Hansen's Disease, but were not yet aware of it. When we arrived, we found the family gathered in the back of a beachfront cabana that they owned and maintained. The space was small, with very poor ventilation and little light – ideal conditions for the transmission of Hansen's Disease. Before I spoke with any of the family members, Dr. Holliday first took the time to explain several facts about the disease, including specific information on its symptoms and the modes of transmission. After she had concluded speaking and running diagnostic tests on the family members, I then took the opportunity to use my questionnaire. I first spoke with the mother of the family, who also happened to be the only individual carrying Hansen's Disease. Although she had just finished speaking with Dr. Holliday, this specific patient actually demonstrated one of the lowest awareness levels of all the participants. She could not explain the disease's symptoms, modes of transmission, or its treatment process.

Although patients displayed various levels of understanding and awareness concerning Hansen's Disease, they were more unanimous in their opinion regarding the illness and prejudice. 66% of the participant group strongly agreed that in the public eye, Hansen's Disease is discriminated against. These responses took a number of different forms:

“Many people have stopped coming to our house. We do not talk about the disease a lot, but we can see that people know. Why else would they stop coming? This only started when my husband discovered he was sick, but now that I have the disease as well, the situation is getting worse” (Interview I4, November 21, 2006).

“I know people who do not like to talk about this disease because they are afraid of it and what it does. People are embarrassed because they think it is a really bad disease, so they never share information” (Interview I7, November 22, 2006).

“Of course there is a prejudice against Hansen’s Disease. Many people have this prejudice. Before, when I did not know I was sick, I had the very same prejudice. I thought a lot of terrible things about patients and how the disease would affect them. I have only started to change since I became sick and learned more about the disease” (Interview I11, November 23, 2006).

“I think there is a really big lack of information about the disease. People do not understand what it is or who it affects. As a result, people continue to discriminate against patients. I have never felt any discrimination, but as I told you, my case is very minor and hardly visible, so people don’t know I have the disease. If they did, I’m sure I would feel a lot of discrimination” (Interview I16, November 29, 2006).

Talking with Other Individuals

This section aims to uncover how other individuals, not directly afflicted by Hansen’s Disease, perceive and understand the illness. The participants are divided into two groups: inter-domiciliary contacts (generally family members of the patients) and individuals drawn specifically from the middle and upper classes. It is important to view the responses of these two factions alongside one another because they present interesting perspectives on how socio-economic standards can affect an individual’s conceptualization of Hansen’s Disease. Members of both groups were presented with the exact same questions, which varied slightly from those subjects posed to the patients themselves. In general, however, the aim was similar: determine the individual’s knowledge of the disease and compare that understanding against their perception of prejudice and stigma.

Inter-domiciliary contacts:

The first question posed was in yes/no format: do you recognize the phrase Hansen’s Disease? I originally hypothesized that the majority of inter-domiciliary contacts would reply in the affirmative, at least recognizing the name of the illness. As my experiences with the patients demonstrated, however, many people remain unaware

of the disease's name. When answering, most of the participants seemed hesitant, implying that the word sounded familiar, but that they did not possess much information beyond that. Interestingly, a large majority of inter-domiciliary contacts (80%) recognized the word "hanseníase," but that includes those participants who demonstrated the hesitation as described earlier.

For those participants who admitted to know what Hansen's Disease is, they were then asked to describe where they had first learned about the illness. My expectation was that most inter-domiciliary contacts would obtain their understanding through conversations with those family members who were also patients of Hansen's Disease. Not surprisingly, therefore, 100% of the participants who said they knew what Hansen's Disease is, listed "by way of another patient" as one of their sources. Another 75% also indicated that they had learned something about the illness from posters advertising information on Hansen's Disease. Such placards are ubiquitous within SESAB but in very few other places, so it is hard to determine whether the participants obtained this information only after they started accompanying their loved ones to the health post, or whether this information reached them prior to that. One contact reaffirmed this question when she stated, "there are so many posters here, I'm sure I must have seen one before my daughter became sick" (Interview I3, November 20, 2006).

Of the total group of inter-domiciliary contacts, only 20% could explain how Hansen's Disease is transmitted. Even then, their levels of awareness varied. One participant explained that people caught the disease "through speaking," a rudimentary explanation of the fact that bacillus resides in the upper-respiratory tract. The respondent credited one of the doctors for having provided him with this information (Interview I14,

November 27, 2006). On the other hand, the only inter-domiciliary contact with a college education, provided a full and accurate assessment of the modes of contagion of Hansen's Disease, including details on the need for prolonged and intimate contact between individuals (Interview I8, November 24, 2006).

A larger percentage (50%) correctly identified some of the symptoms of Hansen's Disease, but like the patients themselves, their answers were generally vague and incomplete. "Hansen's Disease is the spots on your skin," explained one respondent (Interview I12, November 22, 2006). His response echoed the broader picture: most of the inter-domiciliary contacts were not able to go into greater detail about the disease's symptoms. Only one participant noted that the marks on the skin generally lose their sensitivity (Interview I8, November 24, 2006).

Once again, only half of the inter-domiciliary contacts (50%) associate Hansen's Disease with a stigma or some form of prejudice. Even amongst those respondents who believe the relationship exists, their explanations that discrimination was generally mild and harmless.

"Some of my neighbors tell me that I should not wash my clothes in the same tub as my daughter's clothes. They say the disease will spread from me to her, and that I need to be more careful now that the disease is in our house. I have never seen them say anything to [my daughter], but they probably treat her differently now" (Interview I3, November 20, 2006).

"I think there is a lot of prejudice against Hansen's Disease. My husband always wants me to accompany him to the health post because he is embarrassed about his condition. He never wants to talk about it. Most people do not even know that he is sick because he is afraid to admit to his condition" (Interview I5, November 21, 2006).

"So few people understand Hansen's Disease. There is prejudice because nobody understands the truth" (Interview I8, November 24, 2006).

"Everybody has prejudices. I think that Hansen's Disease also has prejudices, but that is no different from the rest of life. People are prejudiced against many other things as well" (Interview I18, December 1, 2006).

Speaking with the upper class:

As noted earlier, the sampling of upper class citizens received the same questions as the inter-domiciliary contacts. In regards to the first query, which asked the participants to state whether or not they recognized the phrase Hansen's Disease, 100% of the sampling responded in the affirmative. I had expected that a majority of the respondents would respond as such, but I was surprised to see that not a single individual was unfamiliar with the term. Nonetheless, I was excited by these results because it would allow me to investigate how many participants had simply heard of the disease, and how many really understood it. (Did they fear admitting to something they didn't know?)

Members of the upper class received much of their understanding of Hansen's Disease from television advertisements and by word of mouth. 70% of the sampling recalled having seen something on the television about the disease, although some retained more information than others: "I remember the advertisement was about Hansen's Disease," recalled one participant, "but I have forgotten most of the messages that were included" (Interview I23, November 21, 2006). Contrast this with another respondent who enthusiastically replied, "I did not think the advertisement was going to be about Hansen's Disease because it began by showing some friends on the beach. I was so surprised when they started talking about the disease that I decided to listen more closely" (Interview I27, November 25, 2006). One individual recalled seeing Hansen's Disease on television, but not in a public health advertisement. "On one of the 'novelas' (Brazil's version of a soap-opera), one of the characters had Hansen's Disease. That was several years ago, so I don't remember what they said about the disease" (Interview I25, November 24, 2006). At the same time, many of the participants were unable to pinpoint

their exact source of information. “[I learned about Hansen’s Disease] in school, I think. I just remember hearing the name” (Interview I32, December 1, 2006). None of the respondents had ever talked to a patient of Hansen’s Disease, nor had it ever been brought up during a medical consultation.

When questioned about the transmission of Hansen’s Disease, 80% of the grouping claimed to have some understanding of the process. Every single one of these respondents, however, cited physical conduct as the principal mode of communication. As one individual stated, “You get it when you touch the skin of somebody who is already infected, right?” (Interview I28, November 25, 2006). While the bacillus can be transmitted through physical contact, incidences of this are rare. Communication of this type requires that an individual has contact with an open lesion of a patient. Lesions, however, are not a clinical manifestation of most types of Hansen’s Disease. None of the participants, meanwhile, mentioned speech as a form of transmission, nor did they include that communication only occurs after extended periods of contact.

Many of the upper class participants had difficulty verbalizing their understanding of the symptoms of Hansen’s Disease. Almost all of the respondents (90%) said they knew the symptoms, but then struggled to explain themselves when I asked them to elaborate. One participant stated, “I know that Hansen’s Disease affects the skin, and I think you develop sores on your body” (Interview I23, November 23, 2006). This response ran parallel with many of the other participants who believed sores and open wounds, rather than discolored spots, were the disease’s principal symptoms. 20% of the respondents also associated physical deformities with Hansen’s Disease.

The entire sampling of upper class citizens asserted that there exists prejudice against patients of Hansen's Disease. Two characteristics were common throughout their answers: first, most were unable to express what shape that prejudice takes and, second, a reference to the disease's history. In addition, many of the respondents pointed out that they themselves did not harbor such prejudices, but instead, they were simply reflecting on the situation as a whole. The quotations below demonstrate these various tendencies.

“This is such an old disease and people have been afraid of it for a long time. I don't think I would ever discriminate against somebody with the disease, but I have never met a patient. There are a lot of people who just don't understand” (Interview I23, November 23, 2006).

“I don't really know about the prejudice, but I think it exists. I think that it has been passed down from generation to generation” (Interview I30, November 30, 2006).

“So many people talk about Hansen's Disease and its stigma. The stigma must affect people, and they probably develop a lot of prejudices because of it” (Interview I24, November 22, 2006).

“There is a very strong stigma associated with Hansen's Disease. People believe it's a dirty illness, an impure illness, an ugly illness. People have thought this for a very long time” (Interview I28, November 25, 2006).

Analysis of Findings

All sectors of Brazilian society demonstrate a fault in awareness concerning the clinical issues (modes of transmission and symptoms) of Hansen's Disease. This lack in information is enacting predictable effects on the prevalence of the disease. All of the health officials agreed that unfamiliarity amongst individuals at the highest risk to contract the illness represents a major obstacle to combating Hansen's Disease. Until information levels increase, undiagnosed cases will remain, infecting others, and the endemic will persist.

Contrary to a lot of research conducted on Hansen's Disease, the patients in Ilhéus expressed relatively little concern over stigma and prejudice. I entered this project expecting patients to convey a much more fatalistic view of their condition. Such opinions generally manifest themselves in the form of psychological issues: mental struggles, stemming from the disease's reputation, that plague patients and cause them to become consumed by their condition.

In this instance, however, prejudice seems to be a function of education and wealth. The patients, who generally were victims of persistent poverty, had little education and even less exposure to information on Hansen's Disease. Their lack of awareness regarding the illness did not stop at symptoms or transmission: they even failed to notice that their disease was one of the most discriminated against maladies in world history. Wealthier individuals, on the other hand, demonstrated minor familiarity with the disease and its clinical manifestations, but the recognition of the name was sufficient to draw connections with leprosy and its social implications. As a result, their overall opinion of the disease tends to carry a very negative tone. The likely reason behind this stems from the fact that within this class, a diagnosis of Hansen's Disease represents a direct threat to their public image and to the sense of identity that they attempt to project to the social world and to themselves.

Variance in perspective based along socio-economic status draws into question how individuals are educated about the disease. For patients and their family members, the majority of information came by way of medical professionals and government-sponsored posters. Members of the higher classes, however, had trouble identifying their sources of information, potentially implying that they learned about the disease by simple

word of mouth. In other words, rather than receiving accurate information from trained professionals, wealthier individuals are constantly exposed to the public opinion of the disease that already exists within their social circles. The negative connotations and subsequent prejudices, therefore, become self-perpetuating: until there is an effort to re-educate these individuals, perceptions will be passed from one generation to the next.

We should not, however, downplay the importance of also further educating the poorer classes. These efforts, moreover, should not just stop at the patients themselves. To really affect a difference, education efforts must reach the population as a whole. The irony behind current efforts is that the major medium for disseminating information – television – is not necessarily the most effective for reaching those individuals most in need of facts.

While efforts by the World Health Organization and government health ministries have been very effective in making information available and providing treatment for diagnosed cases, there have not been sufficient efforts to go to communities one at a time, help people understand the disease, and make new diagnoses. The WHO expressed similar concerns stating that “Information campaigns about leprosy in high risk areas are crucial so that patients and their families, who were historically ostracized from their communities, are encouraged to come forward and receive treatment” (WHO). These campaigns require people to go to the poor, work with them, explain to them what the disease is, how they can receive free treatment, and why patients should not be stigmatized or change their behavior.

In order to achieve the goal of eradicating Hansen’s Disease, it is crucial for those who have the resources to inform and treat to make those abilities available to

populations in need. Today, Hansen's Disease is one of the "forgotten diseases" (WHO). Paul Farmer, although referring to tuberculosis, made an insightful observation that applies equally to Hansen's Disease: because these are diseases that primarily plague the poor, they do not receive the proper attention, funding, and effort from the wealthy that control the resources (Farmer 200). Hahn picks up on this same point, arguing that the misallocation of resources is a major obstacle in solving public health issues; they are not conveyed to the populations in need (Hahn 4). In the case of Hansen's Disease, multi-drug therapy is a very effective form of cure, yet the illness still remains a problem. We are, therefore, not dealing with a "treatment failure", but rather, a "failure to treat" (Farmer 267). "If a deep analysis of the structure of our society and the institutional health system were realized, we would arrive at the shocking conclusion that there is a larger interest, almost unconscious, in forgetting rather than effectively curing" (Os Desafios da Cura).

Neglect of this sort, however, is not limited to wealthy individuals. Many patients themselves demonstrate a similar desire to forget, although in much more subtle ways. We can begin by examining the differences in physical mannerisms between the majority of patients with little or no education and the two patients with college degrees. The high level of understanding amongst the more educated patients reinforced their ability to act comfortably. The more introvert tendencies of the uneducated patients, however, suggests that they are aware, perhaps only subconsciously, of the fact that they do not understand their disease. In response to such a realization, these patients create a self-imposed separation, manifested in their desire to keep a distance from others, including myself. At some level, these patients understand there is something different about them: they have a

disease. Their inability to explain this condition, however, spawns uncertainty and discomfort, two characteristics often associated with stigmatized individuals.

Discomfort amongst patients, furthermore, inhibits their ability to effectively learn about the illness. The symbolic weight associated with being “diseased” is easily identified in the relationship played out between doctor and patient. The research demonstrates that the majority of the patients revealed a need for improved communication with their health professionals, both in further explaining the biological components of the disease and taking into consideration the symbolic dimension of the patient’s daily life. Instructional tendencies must account for the perceptions of the patients regarding their condition. Excessively technical explanations tend to confuse the patient and, potentially, contribute to the psycho-cultural problems associated with Hansen’s Disease.

Summary of Findings

Amongst patients, inter-domiciliary contacts, and members of the upper class, there exists a fairly consistent fault of information regarding Hansen’s Disease. The majority of participants have difficulty identifying the clinical characteristics of the illness (symptoms and modes of transmission). Of the three sectors, only the upper class demonstrated a consistent familiarity with the illness, as evidenced by their acquaintance with the phrase Hansen’s Disease.

Several patients and inter-domiciliary contacts cited examples of prejudice brought on by Hansen’s Disease. These examples, however, were both less frequent and less severe than I originally expected. All members of the upper class believe that the

disease is associated with some type of prejudice. Such tendencies are attributed to the fact that these participants were more likely to view Hansen's Disease and leprosy as the same illness.

The prevalence of the disease is likely much higher than official statistics suggest. Many individuals are probably living with undiagnosed forms of Hansen's Disease, but they are either unwilling to receive treatment, or unaware that they are sick.

The spread of information concerning Hansen's Disease faces several challenges. First is the mobilization of support to commence public information campaigns. Such campaigns would need to be directed at all sectors of society, but special emphasis should be given to the endemic populations. Another challenge facing the spread of information is the precarious relationship between patient and doctor. Health professionals do not take into consideration the social contexts of their patients, which inhibits the flow of information. In turn, patients feel uncomfortable around some doctors and nurses.

Suggestions for Further Research

There is good reason to consider investigating what patients know about leprosy. That is to say, further research might examine what percentage of patients actually know that Hansen's Disease and leprosy are used synonymously in many societies. How does this alter their perception of their illness? Are they more afraid now than they were before? Such questions would provide a more complete picture of the disease's contextualization, because as it stands now, drawing broad conclusions are difficult when many participants are not aware of their disease's name.

When available, research should also be focused on patients of Hansen's Disease who come from parts of the upper classes.

More definite studies should be conducted in researching how a fault of information affects the prevalence of Hansen's Disease. In this project, assumptions can be drawn on this debate, but more conclusive data is definitely needed. Doing so would help determine the barriers to overcoming the illness as a question of public health.

Conclusion

The eradication of Hansen's Disease in Ilhéus is a case example of the importance of the sociology behind the persistence of disease. Scientific and medical cure-alls have not been shown to effectively control the illness, forcing a closer look into the socio-cultural factors that influence the epidemiology of Hansen's Disease. Ilhéus must investigate perceptions of Hansen's Disease that have hindered proper control efforts and improve the dissemination of information to its populace. In order to alleviate the current situation, it is important to start by raising the level of understanding, so more individuals will become aware to the disease's existence and their responsibility in combating its persistence. Until this is achieved, misconceptions about Hansen's Disease will continue, indefinitely complicating the detection and treatment process.

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Annex

Chart 1: NUMBER OF CASES OF HANSEN'S DISEASE AND DETECTION RATE IN THE MUNICIPALITY OF ILHÉUS, BAHIA. 2001 – 2005.

Year	Number of Cases	Detection Rate
2001	18	0.81
2002	15	0.67
2003	23	1.03
2004	20	0.90
2005	15	0.58

Chart 2: CASES OF HANSEN'S DISEASE, ACCORDING TO CLINICAL FORM, IN ILHÉUS, BAHIA. 2001 – 2005.

Year	Paucibacilar	Multibacilar
2001	04	14
2002	06	09
2003	13	10
2004	09	11
2005	05	10

QUESTIONÁRIO - INTERDOMICILIAR

Esse questionário será usado para uma pesquisa que é parte do School for International Training, um programa do intercambio entre estudantes da faculdade dos Estados Unidos. Essa pesquisa é sobre o conhecimento geral da Hanseníase aqui no Brasil, e sobre a realidade da percepção pública da doença. Se for aceito, nós valorizamos muito da suas respostas. É importante lembrar que todos os dados serão confidenciais. Nós iremos descartar o questionário depois do término da pesquisa em Dezembro.

1. Sexo (escolha um): Masculino Feminino

2. Idade:

3. Grau de instrução:

4. Tem emprego (escolha um)? Sim Não

Se resposta foi SIM:

1. Que tipo de trabalho? Contrato CLT Outros

2. Quanto ganha por mês? Menos de um salário Um salário

Dois salários

Três salários e mais

5. Você sabe o que é a Hanseníase? Sim Não

6. Como aprendeu sobre essa doença? Televisão Rádio Através de um amigo

Através de pessoa portadora Numa consulta médica com profissional de saúde

Posto de Saúde Outro: _____

7. Você sabe como essa doença é transmitida? Sim (explique abaixo) Não

8. Você sabe sobre os sintomas da doença?: Sim Não

Se a resposta foi SIM, conhece outra pessoa com esses sintomas? Sim Não

9. Você sabe de um estigma associado com essa doença? Sim (explique abaixo) Não

QUESTIONÁRIO - PACIENTES

Esse questionário será usado para uma pesquisa que é parte do School for International Training, um programa do intercambio entre estudantes da faculdade dos Estados Unidos. Essa pesquisa é sobre o conhecimento geral da Hanseníase aqui no Brasil, e sobre a realidade da percepção pública da doença. Se for aceito, nós valorizamos muito da suas respostas. É importante lembrar que todos os dados serão confidenciais. Nós iremos descartar o questionário depois do término da pesquisa em Dezembro.

1. Sexo (escolha um): Masculino Feminino

2. Idade:

3. Grau de instrução:

4. Tem emprego (escolha um)? Sim Não

Se resposta foi SIM:

3. Que tipo de trabalho? Contrato CLT Outros

4. Quanto ganha por mês?

5. Você sabe o nome de sua doença? Sim (escreva abaixo) Não

6. Como descobriu que tem essa doença? _____

7. Antes de saber que tem a doença, você já teve algum conhecimento sobre ela? Não
 Sim (explique): _____

8. Você sabe como essa doença é transmitida? Sim (explique abaixo) Não

9. Você sabia, antes de fazer tratamento, que o Brasil oferece medicamentos e tratamento gratuitos? Sim Não

10. Você recebeu ou sentiu qualquer tipo de preconceito em saber que tem essa doença?
 Sim (explique abaixo) Não
