No Leper Left Behind: Kinship, Identity, and Modernity in an Indian Leprosy Colony

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No Leper Left Behind:
Kinship, Identity, and Modernity
in an Indian Leprosy Colony

By Heather M. Pearson

Submitted in Partial Fulfillment of the Prerequisite for Honors in the Department of Anthropology at Wellesley College

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Forward

The Making of a Medical Anthropologist

Does leprosy still exist?

What does it mean to be cured?

Does a disease really end when a doctor says so?

If so, why am I still scared?

These questions raced through my mind as our white van bumped along the dirt road. I came to Ghana as the Co-Chair of the Global Outreach Committee (GOC), a subsidiary of Wellesley’s Pre-Medical Society. Once called the Missions Committee, GOC organized and facilitated medical-based engagement opportunities for the college’s pre-medical school students to travel the globe and interact with those of different epidemiological and epistemological histories.

In the summer of 2011, we traveled by car, airplane, and then van to the city Ho, district capital of the Volta Region in the north of Ghana. The group consisted of six Wellesley students, including myself, and a male student from University of Michigan. The average age of GOC’s maiden trip to Ghana was 19 years old. We were children; maybe not according to the IRS and the Army, but in terms of our lack of an ability to examine our relationships to the world outside of our post-pubescent minds. Although we came to Ghana with good intentions to help others, deliver westernized healthcare, and see a bit of the world, we were ignorant that those intentions were camouflaging the
intentions of hundreds of years of oppression, racism, and extermination. We were unknowing agents of neocolonial authority.

It was an overcast morning the day I saw my first leprosy patient. We were briefed the night before that the next day was allotted for medical outreach. In the past, ‘medical outreach’ had included trips to rural villages to help vaccinate infants, as well as visits to elementary schools to perform routine physical examinations. The jobs were loud, busy, hot, and in most cases, required a higher degree of medical specialization then our generic training granted us. But that didn’t matter to the NGO, and so it was up to the will of the student to not give into the temptation to assume medical authority and to play doctor to real patients.

We piled into a white Toyota an hour after we were supposed to depart from the regionally affluent home in which we were staying. After we were settled in our seats, the leader of the Ghanaian-based NGO informed us we would not be working that day in a village, as we had assumed would be the case, but instead we would drive just a few miles down to the road to clean wounds and apply bandages to those who lived in a colony built for cured Lepers.

The lush Ghanaian countryside seemed too steady as I looked out of the van’s dusty window. A single mountain cut through the hazy sky. Termite mounds rising above the green underbrush marked the road from the countryside. The red of the soil kicked into the air by the spinning tires caused the midday light to cast a sepia glow on everything I could see.

The summer of 2011 was the second time I had been to the continent of Africa. In 2009, I traveled to Kenya and Tanzania with 15 other American students. We were
volunteers through a San Francisco-based *Wilderness Adventures* program designed to create an excursion for privileged overachievers looking to add volunteer experience to their college applications. Our service consisted of painting a schoolroom. After those few days were over, and we were secure in a false sense of the nobility of our actions, we spent the remaining month on safari, shopping for eclectic souvenirs, and scuba diving. It was the type of experience that I, along with my peers described as, ‘life changing’, but in no way did my life change after I returned home.

One evening, at a bush bar where everyone knew my nationality from the light color of my skin, I used the condensation from my Fanta to wash my hands of the day’s dirt. I dried my hands on my shirt only to see the russet mud left streaks along the white cotton. Debs, an Australian expat who called Kenya her home, saw what I was doing and started to laugh. I asked what was so funny, and she shook her head and told me that my shirt was now stained.

I asked why the earth was so red; when in the United States it was brown and black. She took a sip from her beer and told me there was a Shona saying that African earth was stained red from the blood of those who fought to keep it.¹

I thought about Debs and the blood stained soil as we drove to the colony growing larger on the horizon. Although the description is hyperbolic, the deep red color is caused by the oxidation of high levels of soil iron. And after all, iron is a key component of

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¹Shona is a linguistic designation given to distinct Bantu ethnic groups living in modern Zimbabwe and Mozambique. The same anecdote was used in the 2004 film *Blood Diamond*. I am unsure if Debs took this anecdote from the film, but based upon her nomadic lifestyle, I doubt she had seen it before our conversation in 2009. (Doke 1931)
hemoglobin, the molecule by which oxygen is circulated in the bloodstream and is responsible for blood’s rich color.

The night before, as we sat over a dinner of fermented corn and chicken, Richard told us we would be volunteering at the Leprosy Colony the next day. We were to travel to Schoonhoven, a community only a few miles from the home in which we were staying, to clean and bandage the ulcers of its residents.

Schoonhoven, named for a town in Holland that raised money to purchase land and build structures for patients evicted from their clinic-side hovels, housed about 40 fortunate individuals who were deemed pathogenically cured of a disease until that morning I knew to only exist as a biblical allegory for sin.

I imagined the sight of rotting limbs and draping veils. I heard tuneless bells ringing and cries of ‘unclean, I’m unclean’. I smelled putrid filth and tangy coagulating blood. Although I sat in a modern van, medieval images of leprosy represented and reinforced in the collective occidental conscious of my upbringing clouded my compassion. I was afraid.

On the radio, a Ghanaian artist rapped the summer’s most popular hit. Instead of singing along to the lyrics, we sat in silence. From my window, I could see a series of identical cement structures built in neat lines radiating from a central covered pavilion.

The van parked where the road stopped. The remainder of the journey had to be accomplished on foot. As we began the process of unloading our supplies, I kicked a rock under the tire in case the brakes gave out. We walked like ducklings following an overgrown footpath in matching blue shirts with ‘Volunteer’ screened on the backs. In
our arms were boxes of gauze and antiseptics. I watched as hunched figures made their way onto the central pavilion of Schoonhoven.

They sat on the ground even though rows of benches were available. They sat quietly as we learned how to clean ulcers common to those with lasting nerve damage from the disease. We formed a circle, standing and leering over the patient, and tried to get a better view at the technical process of wound care without making eye contact with the individual.

One by one, they waited for our unskilled hands to spill hydrogen peroxide on their frail bodies, wipe their red and puss-filled ulcers, and wrap the wounds with white cloth. Bandages were a precious commodity to these residents, who enjoyed no formal clinic or first aide facilities at the colony. And so as the supplies we brought began to run low, our care became more selective. Those with larger more infected wounds got treated. Those with smaller lesions were told to come back another day.

We worked for two hours. The sun cut through the drizzling sky and warmed our backs before the clouds overtook the sky again. The administrator at the colony suggested to Richard that we wrap up our work at the pavilion, despite a number of patients still waiting for attention, and travel to the housing units to tend to those unable to even travel the 100 meters to wait for our care.

The colony is not a self-sustaining entity. They exist from marginal assistance from the community, as well as through charity donations and medical volunteer initiatives. Although the buildings were of good quality, they were themselves a donation, and did not include any way to maintain or sustain existence for those with a high level of medical needs. It was clear that the need far outstripped the resources. This
manifested in the unyielding rule that only those with active leprosy ulcers were welcome, and once healed, the residents were expected to move on to allow another patient to enter.

It started to rain as we wandered independently though the colony searching for those who needed our help. Puddles pockmarked the earthen paths along the neatly constructed barracks. The smell and the color of the puddles made it unlikely the liquid came from the sky.

It was there I saw a man. He was maybe 60 years old and sitting on his stoop with his back slumped against a pillar. He looked to me and motioned to a large pink wound of the bottom of his foot. I couldn’t see the entire wound. It extended along the whole of the sole of his foot resting on the ground. I walked closer to him to get a better look. My plastic bag of medical supplies was much lighter than it had been when we entered the colony, but I knew I still had enough to help him. Although English was an official national language of Ghana, most of the rural population of Ho spoke Ewe, a tribal language. I held up my bag and raised my eyebrows. He looked into my eyes and nodded.

I knelt down so our eyes were the same level. He lifted his foot from the ground and held it up so I could see the work I had to do. I didn’t understand what I saw. It didn’t look like the other wounds I had spent the morning treating. It was large, about the size of a grapefruit, but relatively shallow. I put my gloved hand next to the wound and felt the heat from the red and pink tissue. Charred skin and clotted blood ringed the wound.

“Don’t waste any bandages on him,” Richard said. He had come to find to me.

I looked at the man as I asked Richard why? The man looked to Richard and spoke in a gravely voice words I didn’t understand.
Richard walked to where I was crouching and motioned for the man to hold his leg higher so he could study it without bending down. I watched Richard’s face as he examined the man’s foot. The patient said something to him in Ewe and motioned to the foot. Richard made a disapproving chortle deep in his throat.

“He did this to himself,” Richard defended, “look, you can see the burn marks.”

I asked Richard why a resident would burn himself and prevent his healing.

“Because this place is only for people with unhealed wounds,” Richard rolled his eyes and shifted his posture impatiently, “just pour some iodine on it and leave him.”

The drizzle threatened to become rain and I handed the bag of bandages to Richard. He gave me the brown iodine bottle and walked away.

The biomedicine of the West had proudly declared this man cured of leprosy. But he was artificially prolonging his relationship with that world by burning his flesh. I didn’t understand why a cured man would do such a thing. Until I realized that a fundamental rift must exist between what it meant for this man to be cured on paper, and for this man to be accepted into the society from which he came as cured.

The man’s sunken eyes looked past the horizon. I stood over him and did as I was told. I poured the antiseptic over his burns and watched the red earth turn brown with iodine and puss.
Image 1: Three barrack halls of Shoohoven Leprosy Colony, Ho, Ghana. Students walking to see if immobile individuals needed wound care in June 2011.

Image 2: Students observing fellow student tend to the wound of woman with Hansen’s Disease in Pavilion of Shoohoven Leprosy Colony. NGO leader, Richard, is visible as leftmost standing figure.
Introduction:

What is disease? At first glance, the answer to this question seems self-evident. From a young age, members of the Global North are surrounded by symbols and metaphors that reinforce and re-inform cultural frameworks of disease as a zoetic entity in opposition to ones Healthy Self.

One such culturally saturated metaphor represents metastatic cancer cells, or the unwanted growth of self, as transforming from Self to Other. The conceptually categorized Other is inherently insidious for its very presence has been socioculturally reinforced as a symbol for the unknown of death (Zemgac 2010). Cultural Metaphors build upon this understanding, depicting a diagnosis as a decree of war, in which a battle will be fought, with infinite influences and drastically varying odds, between life and death (Kukaswadia 2013).

The relationship between culturally constructed metaphors of illness and biological understandings of disease is a point of study for medical anthropologists, and yet illness and disease are not independent entities. Culturally informed understandings of illness and biological understandings disease are explanatory models used to contextualize and rationalize ill-health events within the context of patient’s sociocultural identity (Helman 1981).

Hansen’s Disease, known by its historical name of leprosy, illustrates the tension between biological understandings of disease and culturally informed understandings of illness. These cognitive symbols reinforce stigmatizing metaphors of those with leprosy as biocultural ‘Others’ and construct a cultural framework of social and spiritual sin entwined permanently in the social identity of the individual (Harris 2011).
Leprosy is not just a disease. A disease is a defined pathological process that affects a body. It has a diagnosis, a common set of symptoms, a prognosis, and, in most cases, a treatment (Scully 2004). Hansen’s Disease (HD), caused by a specific genus of mycobacteria, is a disease. HD is characterized by a chronic bacterial infection that, if left untreated over the course of many years, can lead to permanent nerve damage and loss of sensation in the outer extremities like the hands and the feet. HD itself is rarely a fatal, and is easily and consistently cured through a simple multi-drug therapy of three common antibiotics (CDC 2013). HD is a disease, but its historical name of Leprosy is not.

And yet, this illness is still a powerful medical reality for those afflicted in many emerging economic powers. Despite its highly curable nature and the extraordinary prevalence of natural immunity in the human population, a diagnosis of leprosy can destroy not only the lives of its victims through stigmatization and social abandonment, but the families from which the victims originate through losing someone able-bodied (Weiss et al. 1992).

Whereas the perceived influence of any illness upon the collective cultural conscious are highly variable and dynamic, disease is a scientific entity that exists in an attempt to describe the indiscernible existence of the natural world (Scully 2004). Leprosy is a social illness with historical, biological, and institutionalized evidence of the long established culturally informed biological disease within the collective cultural conscious. It is a constructed illness category imbued with individualized narratives reinforcing themes of poverty, and inequitable sociocultural diffusion of power and privilege (Sabater 1999 trans.).
Charged with historic symbols and metaphors for sin, leprosy has faded from the Global North’s biocultural conscious through improved access to health services and of medicalized interventions. This diminishing of access to experience-based knowledge of HD strains the ability to dispel historically understood discourses surrounding the illness and the disease within these privileged communities (Caine and Roberts 2014).

Yet despite its biomedical absence, allegories of leprosy and the social construct of the illness are continually reinforced and dispersed within the collective Western conscious through references in religious and historical texts. Therefore, the knowledge gaps that exist between the symbolic illness of leprosy and the biological disease of HD are not dispelled, and lines between biology and society blur and misinform medical and social disease discourses.

HD is a disease, part of the modern epidemiological profile of humanity, but as I experienced first hand while discussing my experiences in Leprosy Colonies with friends and colleagues at home, the presence of leprosy outside of religious and moralized cultural constructions were not known. In addition, understandings of the disease were informed through biblical representations of ghosted figures ringing bells and trailing body parts. Through two years of discussion with educated and informed members of society, I saw a continual reinforcement of the discursive culturally informed narratives of the severity of the disease of leprosy, as well as a complete lack of knowledge regarding the pathology of the disease.

HD is still a part of the global epidemiological profile. Those most at risk for contracting the disease are those living in endemic areas with low standards of living including contaminated water and insufficient diets. Of the estimated 200,000 people
with leprosy in 2011 (down from half a million in 2004), approximately 70% of these cases occurred in the Republic of India (WHO 2009). India, known for its rapid urbanization and rigid social stratum, is also speculated to be the birthplace of the disease demonstrated by genetic and paleo-physiologic evidence (Robbins 2009).

In the context of the Indian subcontinent, stigmatization of leprosy extending from religious understandings of its presence being a divine symbol for sinning in a past life. Western cultural understandings of disease and illness, institutionalized during colonialism, also influence symbolic logics imposed upon those with leprosy long after pathogenic agent of HD has been eliminated. Based upon my ethnographic experience at the Indersh Leprosy Colony, the presence of Western Biological Medicine (WBM) and its Modern Empiricism alters specific cultural logics from which leprosy stigma originates, however the stigma against leprosy, or those labeled as ‘Other’ in the construction of identity, is reinforced in the cultural conscious through the use of Western scientific discourse.

Western informed presentation of HD as a biological artifact and symbol of historical leprosy frames a medical landscape in which individuals living with HD in a urbanizing nation like India, already experiencing varying degrees of localized stigmas associated with biological and psychosocial presentations of the disease, are further stigmatized as not only a representations of culturally constructed disease metaphors, but as biological reliquaries of pre-modernity themselves. Yet the stigmatization of these individuals unifies them within the medical landscape of the colony and allows the creation of equity-based modern kinship structures, independent of social and national boundaries.
But how does WBM and modernity inform understanding of stigma and society in India? And how do structurally, socially, and physically disadvantaged individuals, cured of HD but still socially labeled a ‘leper’, construct kinship and meaning? Those were some of the question I sought to understand through the lens of medical anthropology when I began this project.

This anthropological examination into the relationship between Indian Modernity and the social illness of leprosy is informed by biological, historical, and ethnographic evaluations. Ethnographic fieldwork was completed during the summer of 2012 in Dehradun, India, a major city in the foothills of the Himalayas. My work was made possible by KHEL, (Kindness, Health, Education, Laughter) Charities. KHEL was founded in 1986, when a beggar with leprosy came to the door of a wealthy Brahman family. Instead of turning him away, they gave him milk and he told them his story. From that instance of kindness, a charity was founded dedicated to providing equal opportunity through education, support and employment of the urban poor, regardless of ethnicity, caste, gender, religion or sexual orientation.
Part I: The Disease of Development

A disease is something that is abnormal and unknown. A disease can lead to interactions with intimidating doctors in white coats with big vocabularies. The presence of disease implies the absence of the health. These understanding of disease permeates the collective Western biocultural conscious, and is reinforced through campaigns, advertisements, and interpersonal communications (Sontag 1978). Yet, whereas a disease is defined by biological and scientific presentations, illnesses are culturally defined maladies that both inform, and are informed by, the biology of the disease, as well as the cultural construct of the disease within the collective social conscious (Helman 2001).

In the 21st century Global North, Hansen’s Disease is an uncommon epidemiological occurrence, and exists in the collective conscious through allegorical and illustrative religious texts. These moralizing texts serve one of the most pervasive sources of popularized knowledge about the condition, and inform cultural understandings thereof (Caine 2014). I consistently observed this phenomenon when discussing my research with various members of Western society. I was asked question like, “Leprosy, does that still exist?” and, “I thought that was only in the bible?” This pervasive continuity of association is evidence of the deep reach of religious and moralized pathogenic associations of the disease throughout the Western cultural conscious.

And yet, Hansen’s Disease is a biomedical and social reality for many individuals living in the Global South. This is seen throughout the Republic of India, a nation of rapid urbanization and economic development with unique sociocultural understandings of self and social history. Using the tools and theories of medical anthropology,
constructions of identity, conceptions of modernity, and creations of kinship can be examined and used to and to contextualize the lived experiences of those with individuals connected through the leprosy colony.

**The Methodology of Medical Anthropology**

Medical anthropology is a branch of the discipline of anthropology devoted to the study of the relationship between the physical manifestations of disease and social understandings thereof. Medical anthropology examines the relationship between illnesses, a subjective experience informed by an individuals relationship with their culture, and disease, the biological aspects of pathogenesis. It is the role of medical anthropology to understand a disease from a broader, more holistic, perspective and to inform the biological understandings of disease and illness with the contextualization of culture, society and history.

It is from this perspective, the way in which a patient understands his or her experience of disease is readily informed not only by the individual’s cultural and socioeconomic background, but also by the individuals *Imponderabila of Everyday Life*, and this knowledge offers us valuable insight about how to heal not only a condition, but a person (White; 2009, and Malinowski; 1922).

Within the social sciences, medical anthropology is relatively new to the scene. The age of European Empires ended with World War II, during and after which independence movements in former European Colonies established autonomy from their Colonial governance. The Age of Nation States, the name given by Historians of the
second half of the 19th century, saw with it changes in medical anthropological discourse and interpretation. Early in its history, medical anthropology was used as a tool for the Westernization of public health initiatives in freshly de-colonialized nations (Alexandrakis 2011). During this time, when medical anthropology had a strong applied emphasis, disease was viewed as ‘paradigmatically biological’ and therefore independent of the influence of cultural discourse, a defining understanding in the discourse of Western medicine (Alexandrakis 2011).

Traditional Western medicine is informed by a single principle: the human biochemical response to disease is ubiquitous (White 2009). Humanity is a single species and therefore responds to medicalized interventions in similar capacities. This understanding of the equality of disease informs WBM-based initiatives to take effect in regions independent of regionalized cultural constructions of health and illness.

The field departed from epistemological understandings of systems of health prevalent in the 1950s and 1960s, to a more interpretive approach at the turn of the 20th century. This interpretive understanding of medical anthropology conceptualizes disease not as an absolute biomedical reality, but instead as being informed by culture in the subjective and socialized experience of illness (White 2009).

And yet, within a society where the discourse surrounding medicalized illness and health is not uniform as the result of influences of Westernization on the national conscious, the ways in which interpretive and epistemological understandings of health and society influence and inform each other become an integral part of the national health narratives and constructions of identity and modernity. The following is a review the
theoretical framework by which the conflict between unique systems of health conceptualization of leprosy can be analyzed.

**The Anthropology of Development and Western Modernity**

The ways in which language informs everything; from perceptions of colors, to time, space, objects, and power, have been demonstrated behaviorally and ethnographically for almost half of a century (Roberson and Hanley, 2007; Levinson et al., 2002; Gentner and Boldkin-Meadow, 2003; Lucy, 1992; Fausey et al., 2010). The translation of language of development, and not the transliteration to preserve meaning, is an active member in the social discourse of global development. The ways by which development is defined informs the way in which it is understood in a cultural and societal context. Development can mean activities required to bring about progress and growth; or can be used as a metric by which ‘rates’ thereof can be compared (Frankenberg 1980).

However, historically, development has often been seen as a tool of the misguided application of Social Darwinism as a biopolitical-colonizing agent operating under the Eurocentric understandings that societies develop overtime to levels of higher complexity, and can therefore fit within a teleological progression to Western Modernity. From this conceptual framework, modernity is a reified accomplishment only achievable through social development. Western academics have historically assigned value to societies with greater international economic complexity, and the economical path, or
development, thereof becomes a metric for the social progression of nation state (Seng 2009, Raghuramaraju 2011).

International Development as a social construct was born in the wake of World War II’s destruction. And the concept has gone on to be one the most relevant and dominating cultural phenomena of the 20th century. ‘Development’, as a structural concept, was coined by the Harry Truman, as an explanation for investing in post-War reconstruction and its economic growth strategies (LSE 2013). Without the monetary and social aide of the United States during that period, it is unlikely the devastated European nations would have been able to recover and achieve relative social normalcy as quickly as they ultimately did. It is from this initial success, cultural understandings and perceptions of the interconnectivity of development and external investment has left in its wake a complex and dynamic understanding of Development, to achieve cultural Modernity, as being synonymous with socioeconomic growth (LSE).

Even the work of social theorist, Emile Durkheim, can be used to view development as the process by which increasing sociopolitical and socioeconomic complexity is indicative of a transition between a ‘tradition’ and a ‘modern’, and therefore superior, society. In recent times, development has become associated with the neoliberal movement of planned social change, which can also be interpreted as colonial and neocolonial Western domination of poorer countries.

The anthropology of development examines the construction of indemnity not only within a society, but also between societies. Central themes of the field are the relationship between human similarity and human difference, understandings of Western
modernity, and the terms by which economic and culture integration occurs into the globalized and Western-dominated sociopolitical milieu.

In the wake of World War II, colonized populations rebelled against their war-weary imperial subjugators and thereby, “freed themselves from their subject status” (Barratt Brown, 1963: 189-90). Constitutional sovereignty may have marked the end of colonial imperialism, but it did little to lessen the overwhelming presence of transplanted cultural and economic supremacies dominant in the social and power structures of the restored nation (Kuper 2005).

The discourses within international aide and development initiatives are inherently imbued with neocolonialist ideologies. The term describes the process by which powerful and wealthy countries in the global north invest in vulnerable population and political structures by providing conditional access to medical, social, and economic relief. The condition, whether implicit or explicit, consists of the exportation and supposition of western logics and cultural frameworks upon indigenous peoples (MacFarlane 2012, Mosse 2013).

Responsive to anthropological critique about the neo-colonizing agent of development as a way to impose western-suiting logics and cultural frameworks on non-Western society, the field of International Development has shifted from examining the discourse of power relationships between the Western agent and the society, and has settled now on creating the ethnographic treatment of development as a field of the practice itself (Mosse 2013).

And so international development indicates social processes that are trans-nation, intercultural, multiscalar and involve the interactions of extensive actor
networks with different cultural logics and lived experiences (de Sardan 2005), and is the tool by which Western constructs of self, society, health, and nationhood are exported and institutionally applied to various unique regional and social landscapes.

Constructing Identity and Illness

The dualism of western medicine in its over-valuation of etic cures and under valuation of an emic cures has been examined in the context of the communication between a patient and a physician. To social and behavioral scientists, an etic account is a description and contextualization of an action from the perspective of an observer outside or removed from the cultural understandings of the actor at hand. Conversely, an emic account is a description of an action in terms of meaning to the actor. In this way, an emic understanding of a topic is based upon a holistic understanding deeply rooted within cultural contexts and understandings at hand (Harris; 1976). The tension between biomedical understandings of leprosy and the lived experience of disease offers an example of the tension between emic and etic understandings of health and must be used to understand constructions of health-based relational identity (White 2009).

Identity is complex and dynamic self-categorizing tool by which humans can position themselves in relation to others. Identity imposes a culturally specific framework by which interactions and events of daily living can be contextualized and rationalized by the individual. Identity is multifaceted, with numerous different identities, such as sexual identity, gender identity, and illness identity (Baer 2003).
The philosopher, Michel Foucault, critiques the relationship between biology and identity though outlining the theory of biological reductionism in his 1963 work *The Birth of a Clinic*. He argues the French and American Revolutions, ideologies from which ignited industrialized modernity, also created a meta-narrative of scientific discourse. This discourse presented the medical profession, physicians in particular, as enlightened leaders and saviors with the ability to eventually rid humanity of all of its problems; including mankind’s ultimate enemy: the unknown of death (Foucault 1973).

Foucault argues that much in the same way the discredited clergy of the European Middle Ages maintained social authority through the construction of contextualized explanatory models which rationalized the biological reality of disease, scientific Empiricists of the 18th and 19th centuries assumed this same social authority through redefining use of tangible medical interventions to forgo the impact of disease and death in its entirety through prolongation of life.

This meta-narrative maintained its peripheral influence, Foucault claimed, through what he coined as ‘the medical gaze.’ This concept, integral to the practice and reproduction of knowledge in modern medicine, refers to the psychosocial separation of the biological body from the patient’s identity. Through reifying the body, it can be contextualized and used to construct a field of knowledge, namely Biomedicine. The ability to understand the ways in which sociopolitical, biocultural, and psychosocial distinctions influence the incidence, identification, experience, and outcomes is crucial to cross cultural understandings of medicine and the adaption and success of imported and exported health-related practices (Kleinman, Eisenberg and Good 1976).
The anthropologist and physician, Arthur Kleinman, discussed this difficulty in medicalized communication from an inability to transliterate meaning and experiences across this ‘medical gaze’. Kleinman observed physicians interpret and misinterpret the language of a patient when discussing a disease in their attempts to fit the patient’s description into an etic understanding of diagnosis and a disease.

Language, Kleinman urges, is inherently informed by the cultural and social circumstances of a person, and therefore, the assumptions that words have the ability to convey the same meaning across different cultural barriers, such as across a biomedical/patient divide, is misguided. As such a ‘specialized culture of medicine’ is formed not just as a way to contextualize and understand a disease, but is essential for the very construction of subjective illness identity and reality (Kleinman 1978).

Western Biomedicine (WBM) is based upon the fundamental understanding of a division between the mind and the body. This duality is taken from the work of the 16th century philosopher, Rene Descartes. The so-called ‘Cartesian dualism’ is from the understanding that the nature of the mind, or the nature of the self-awareness of the mind through reflexive thinking, is a completely different and autonomous entity from the corporal and biological body. Descartes goes on to suggest that because of the interconnectivity between the body and the mind, for example, the mind can will the body to move, it is from the combination of the two that a human being derives his or her existence (White 2009) (Descartes; 1998).

It is from the understanding of a dualism of the body and the spirit; the identity and logic patterns of WBM begins to be contextualized. The separation of the corporal matters of existence from the spiritual ones allows the body to be treated and understood
as a piece of bio-machinery. If a machine is faulty, there is a cause and a solution. The WME aims to identify both (White 2009). It is from a predominately mechanistic understanding of health, the experience of a resident that burned his foot to say in the colony despite being cured of the pathogen does not make sense.

In order to understand why being biomedically cured was not enough to allow the patient to return to his natal kin, a holistic approach to illness must be understood. This holistic approach to health and wellbeing takes into account not only the biology of a person, but contextualizes that biology with all of the other extenuating circumstances of a person’s existence, such as culture, socioeconomic status, gender identity, family background and work status. It is through a holistic understanding, the often cited inapplicability and shortcomings of the WME can be transduced into a relevant form a care that best suits the needs of the patient within his or her cultural understandings and lived experiences (White 2009).

And yet, a holistic approach to medicine further complicates and obscures the already intricate scientific understandings of life and existence. And the very presentation of a spectrum-based holistic versus a biomechanical lens through which healthcare delivery systems are understood implies a Eurocentric understanding of a divide between the corporal biology of a patient and his or her spiritual existence (White 2009).

The continued institutional reinforcement of mind-body dualism perpetuates a discounting of the less tangible forms of social existence that can intensify or mediate biomechanical and biosocial responses of a disease. This social logic is reinforced as new generations of doctors and scientists are trained to view the body as a machine that either works properly or breaks from observable and repeatable natural phenomena (Jensen
2011) (Scheper-Hughes and Lock 1987). It is because of this lack of institutional interconnectivity between the social factors that influence an illness and the biology of a disease, individuals biologically cured of a pathogen can still live the social experience of a disease as though they were contagious biological carriers.

This Western value-based system offers a greater emphasis on the physical health of an individual and not his or her contextualized health within his or her society. Nowhere is this more evident that with those pathogenically and etically cured of leprosy, only to still be socially labeled as a ‘leper’ and to experience the social isolation and structural violence thereby enforced in emic cultural conscious. Their social identity was influence by the presence of a disease and reinforced through cultural understandings thereof. Although no active infection was found in the individuals of the Colonies, a socialized label of the illness of leprosy informed the lived and socialized experiences of the individuals decades after the biomedicalized categorization of these individuals as cured.

**Construction the Self and Other**

The exoticized agent of the constitutive Other, as opposed to the understood Self, describes a person’s psychosocial relationship to those internally seen as different than ones self-image. An individual’s understanding of these multifaceted and bioculturally constructed boundaries between the Sames, or Selves with internally identified degrees of Sameness, and the Others informs one’s psychosocial identity (Erikson 1972). When deconstructing the relationship between the Self, the Sames, and the Others, it becomes
apparent these distinctions exist on a dynamic and collective-identity continuum, and not as resolute categories.

The origins of these internalized identity boundaries extend from culturally learned, cumulatively gained, and continually reinforced experiences. This construction of Self informs one’s response to entities outside of culturally conditioned and experientially accumulated social relationships. By anthropomorphizing and Othering the disease state in addition to those with the disease as something in opposition to the healthy state of personhood, one is able to better understand the distortion of Self and fear of the unknown that a biological entity imposes upon the conscious (Jensen 2009).

Therefore, as continued sociocultural interaction informs the degrees of Sameness, the acquisition of experiential knowledge alters one’s understanding thereof. And so while the ‘Other’ remains a fixed category associated with a lack of referential and informative interactive knowledge, membership in that category is fluid and constructed based upon identity.

Although the Self informs internalized construction of identity, identity itself is not a fixed and immobile entity, either. And although the construction of Self and Other is not inherently implicative of social stigmatization or subordination, it has been constructed as such though cultural misappropriation of this paradigm.

Logics for this subdivision are understandable. Only when the Self and the Disease are symbolically divided, then culturally reproduced with metaphors of meaning based upon the relationship duality, or the informative interactions of the Self to the Other, can the biological realities of disease, death, and life be rationalized and contextualized to be used as coping mechanisms not against the disease itself, but for
ubiquitous anxiety towards death and the unknown, of which disease is a powerful and pervasive symbol (Schultz, 1979).

**Power and Illness Metaphors**

The use of metaphors, or the identification and equation of seemingly disjointed entities based upon subjective shared meanings, produce and reinforce communal understandings of a disease. As such, a metaphor becomes a powerful tool to articulate the humanistic emotion of the perceived sterilization of medical diction (Sontag 1973). Such examples of external metaphors being applied to disease are pervasive in Western society. Perhaps one of the best examples of this phenomenon is the pseudo-literal ‘fight’ against cancer.

Cancer is a disease of unregulated cellular growth. Although forms of cancer originate from different pathogenic agents, genetic predispositions, and environmental factors, the underlying renegade pathogenesis of one’s own body unified the biologically variable disease. To contextualize and understand this occurrence, the diseased entity is metaphorically identified in opposition to a healthy disease state (Manderson 1999).

Is it from this understanding disease, according to the WBM, a Disease state is metaphorically constructed as an entity in opposition to the ‘Self.’ The division of disease and health allows for the commodification of the latter by scientific knowledge-based exploration of the former, thereby imbuing WBM as agents of Foucault’s biopower (Rabinow and Rose 2003). The exportation of these Western understandings of the duality of disease and Self are reinforced through the institutionalized systems of
governance, economy, and society in the wake of globalized colonialism. These models are shifted and molded to exist simultaneously with folk health understandings within the collective social conscious.

Access to knowledge regarding empirical explanatory models, though institutionally unavailable to many, is becoming increasingly available through cyber exchange platforms. In this capacity, Western medical reductionism, culturally contextualized and derived from biopolitical and sociocultural historical occurrences of the Western anthropological narrative, is exported to formerly colonialized nations with unique cultural and historical contexts under the assumed authority of modernization and development (Zucker 1979).

The word ‘illness’ demedicalizes itself in the collective conscious to the extent that it no longer represents only a biomedical reality of an individual, but it transcends into a physical manifestation of fear; whether that be fear of the unknown, fear of the other, or fear of our own mortalities. Targeted and successful marketing campaigns enforce these metaphors and understandings (Lowenberg 1994).

Concrete definitions of disease are pervasively insufficient to dispel biocultural stigmas of leprosy, and require baseline fluency through culturally constructed measures of language and meaning in the scientific vernacular (Silverman 2004). These academic luxuries are often not available in developing nations, as they are byproducts of social and economic stability of industrialized and institutionalized nation states. And the attempts to tease apart inherent differences between academic understandings of medical abnormality and cultural understandings of disease have been present in the medical
profession from the early 1980s, and is still a point of debate amongst leading social and physical scientists.

It is from this transliteration of the meaning of words inherently present in the migration of a patient-driven emic understanding of illness to a biomedical etic understanding of illness, not only the words of the patient, but the contextualized words accounting for the cultural and social origins of a patient, must be addressed while compiling a health narrative. Therefore, Kleinman argues, disease is not an entity but an explanatory model (Kleinman 1973 quoted by Good 1994: 53).

Anthropologist Bryon Good furthers Kleinman’s account of the importance of a contextualized medical discourse. Good suggests illness only exists through interpretive activities, such as those involving interactions of biology, social practices, and culturally constituted frames of meaning; and the ways by which that meaning and interpretive practices, “interact with social, psychological, and physiological process to produce distinctive forms of illness and illness trajectories” (Good 1994: 54). Using this interpretive model, Good analyzed the semantic networks associated with the folk illness of ‘heart distress’ in both Iran and in America. He suggests there is an inability amongst empiricist discourses pervasive in medical and ethnographic studies to account for the use of symbolic and culturally specific constructions of illness, often borrowing from the western-valued empiricist lexicon, within their professional therapeutic processes.

But to understand the relationship between empiricist discourses of HD and socialized constructions of leprosy, both perspectives must be analyzed. The *quid pro quo* pressures of globalized aide and development grants to India, as well as the historical presence of remnant colonial infrastructures, have influenced modern governmental and
public health systems towards adopting empiricist rhetoric extending westernized
biomedical constructs as the necessary currency for an informed and *modern* medicalized
patient/physician dialogs. This discursive framework reflects instances of biopower as
access to westernized biomedical knowledge is controlled by access and availability of
education, whereas access to folk understandings of the disease imbued with themes of
original and past sins are reproduced through socialized discourses not mediated by
institutional access barriers. And so as members of the urban middle- and upper- classes
adopt ornamental medicalized discourses of disease informed by personalized and folk
experience with the localized epidemiological profiles, individuals with little social
agency either through traditional social preference or through educational initiatives are
subject to the interpretive contextualization of authoritative illness-based stigma using the
language of the disease.

These medicalized discourses are disseminated within a socially strict society
through their integration with the institutional construct of ‘modernity’ as an education-
based agent of social mobility. This adoption and translation of WBM creates culturally
specific medicalized vernaculars that present illness narratives with symbolic and
relativized meanings that are not necessarily present in the physician’s own psychosocial
background. It is from within this gap between patient intention and physician impact,
and *vise versa*, rifts between illness identities and disease profiles are continually
reinforced.
Part II: The Science of the Stigma

Leprosy transcends all racial and social distinctions, however it is consistently recognized as a disease of poverty. As such a culturally informed symbol as leprosy does not represent a sufficient pathogenic cause. Hansen’s Disease, or the biophysical response of a human body to the pathogen *Mycobacterium leprae*, does.

The biomedical definition of Hansen’s Disease (HD) is a chronic, mildly infectious, bacterial illness caused by the bacterium, *Mycobacterium leprae* (Suzuki 2010). According to the most recent medical estimate by the World Health Organization, approximately 200,000 people worldwide have active *M. leprae* infections, an astounding decrease from the 1.15 million estimated cases in 1997 (WHO 2012). And the majority of cases still center in Asia and Africa. A contributing study suggests an additional 200,000 people are diagnosed every year (Bhat 2012). And yet, there is much room for biomedical hope. Since the disease’s bacterial identification in the late 19th century, its global pathogenic prevalence has steadily decreased thanks to improved screening and treatment (McDougall 1999).

**The Biology of Mycobacteria leprae**

Of all organic existence on this planet, the domain of bacteria is perhaps the most diverse and exciting. These distinctions are earned through tremendous biological robustness and fecundity. These organisms continually outshine non-bacterial competition both in versatility and abundance, and are, perhaps, amongst the most
evolutionarily successful organisms on the planet. Remarkable extremophiles, bacteria are thought to be among the oldest forms of life. Current phylogenetic analysis places their origins an estimated 2.9 billion years ago in the sulfuric and noxious conditions of Achaean Earth (Ryan and Ray, 2004). Although small in physical appearance, averaging just micrometers in length, bacteria are highly dynamic organisms that are key to the stability of both trophic levels and entire ecosystems. Unlike their more familiar eukaryotic counterparts studied in elementary schools, bacteria cells rarely have membrane-bound organelles and yet are protected from their potentially caustic environment by cellular walls (Ryan and Ray 2004).

Most bacteria are classified into two functional categories: Gram positive (GP) and Gram negative (GN). This distinction is based upon a visual response of bacterial cell walls to a dye agent. Like their eukaryotic counterparts, phospholipid membranes imbedded with various protein matrices enclose bacteria cells. However, unlike eukaryotic cells, should the bacterial cellular membrane become damaged, escape of free-floating genetic plasmids could render the cell completely nonfunctional. To ward against membranous damage, cellular walls constructed in three-dimensional mesh-like layers offer physical protection to the cell. Unlike plants and fungi, whose cellular walls are composed of chitin and cellulose, bacterial walls are made of peptidoglycan: a sugar and amino acid polymer. Peptidoglycan also serves to give structural support to a bacterium, including acting against the inherent osmotic pressure of the cytoplasm (Ryan and Ray, 2004).
Cells that turn a deep purple color in response to the stain are called Gram-negative (GN). Most bacteria fall into this category. GN cellular walls are comparatively thin with an inner and outer phospholipid bilayer, sandwiching a thin sheet of peptidoglycan. Decorating the cells’ outer surface are chains of lipopolysaccharides and porins, facilitating extortive and pathogenic functions (Bergey, 1994).

Cells that turn a light red in response to the dye are called Gram-positive (GP). GP bacteria have a thick cell wall with many layers of peptidoglycan and bacterial polysaccharides covering the ancestral cellular membrane. The thick peptidoglycan crust offers a tremendous amount of protection to the bacterial cell, and yet also decreases the rate of reproduction based upon the physical constraints of breaking and building the
walls (Daniels, 2004). GP cells are the category in which mycobacteria; such as *M. leprae* (ML) is placed.

A member of the domain *Bacteria*, the genus *Mycobacterium* is composed of approximately 100 recognized species, out of an estimated 1 billion total bacterial species. The most famous of these biologic agents are *M. leprae* and *M. tuberculosis*, the pathogens responsible for Hansen’s Disease and TB respectively. Mycobacteria are acid fast, gram-positive bacteria noted for high ratios of the genetic base pairs: cytosine and guanine (Ryan and Ray, 2004). The species within this genus are predominantly aerobic and nonmotile, and all share the unique cellular wall for which the genre is named.

This wall is hydrophobic and rich in mycolic acids, whose waxy structure adds additional stability to the surface rich in polysaccharides and peptidoglycans. This unusually thick wall protects these hardy bacteria and is thought to contribute greatly to its difficulty to kill (Bhamidi, 2009). These biological truths set the stage for TB and HD to endure great immuno-environmental hostility while maintaining their pathogenic potency.

In 1873, the Norwegian physician G. A. Hansen first discovered the bacterium *M. leprae* while prodding the skin nodules of patients diagnosed with leprosy (Ingens 2002, Hansen 1874). *M. leprae* the first bacterium to be identified as a causative agent of a disease in humans. Clinically named for Hansen, HD has since been identified as a granulomatous disease of the peripheral nervous system and the upper respiratory track. The primary external sign of active infection are skin lesions (Ryan 2004). Contrary to popular imagination, HD does not cause body parts of those infected to fall off. Instead, the primary infection can cause the individual’s peripheral limbs to numb. The clawed
hands and stumped feet seen with the condition are the result of localized secondary infections flourishing within the immunocompromised patient. These secondary infections can result in bone and tissue loss as well as the reabsorption of cartilage by the body (Ebenezer 2012)

Similarly to its phyletic cousin, the pathogen that causes tuberculosis, a great deal is unknown about the biohistology and biochemistry of *M. leprae*. This is, in part, due to its extraordinary slow incubation and replication rates. In some documented cases, infected patients can live asymptptomatically for 20 years before the signs of the diseases first appear (Suzuki 2010). Unlike many other bacteria, *M. leprae* has also never been successfully grown on an artificial cell culture medium, and the only other naturally susceptible organism, a subspecies of armadillos, is functionally incompatible with a human model for disease (Truman 2011).

It is thought that much of the difficulty with its cultivation surrounds *M. leprae*’s tenuous position as a mycobacteria, in fact, unlike many of its peer species, *M. leprae* is an obligate intracellular parasite, and lacks many necessary genes for independent survival outside a host. This parasitic coping strategy is thought to illustrate an extreme case of reductive evolution (Steiner 2011). It is estimated that less then 50% of its genome codes for functional genes (Cole 2001), a far cry from the 89% coding DNA in *E. coli*, an extraordinarily resilient and well studied species (Saetrom 2011) A biologically inane agent, it is the social and cultural implications of *M. leprae* that leave leprosy forever imbedded in our collective understanding of illness, and not its active pathogenic profile.
Epidemiology of *Mycobacterium leprae*

A disease so riddled with misinformation and mystery, many are surprised to learn not only is HD one of the least infectious human pathogens, but also approximately 95% of the population have natural adequate immunity. Of confirmed diagnoses, over 85% of cases are inherently non-infectious. The 15% of clinical cases that are deemed mildly contagious are thought to be transmitted through miniscule mucosal drops are rendered non-infectious within one week after the very first antibiotic dose (Gasscignard 2013). Despite of dramatic advancement in treatments utilizing a multi-drug therapy (MDT) regiment of common antibiotics, leprosy is still viewed by social and medical scientists as the epitome of stigmatization. This understanding perhaps lies in the historical evidence indicating individuals with leprosy, across cultures, have been continually feared, shunned, and ostracized because of their condition. (Simons 1948)

This relatively mild pathogenic agent, that is compared to the disease profiles of the Ebola Virus, or even TB, exists as a centuries-old marker of ‘sin’ and ‘impurity’ leading to great social stigma, separation, and de-humanization (Kleinman 2009). And yet, in order to begin to approach the lived experiences of leprosy in the modern world, and the implications thereof, we must gain perspective by examining just how long humans have lived with this malady. To answer this, we look to the historical and anthropological records and attempt to deconstruct fragmented clues littered throughout our history. It is from this need, we turn to the past to gain insight about the disease’s present, and direction for depressing its future.
The Paleopathology of Leprosy

Paleopathology, the study of disease in the fossil record, is an integral part of the field of physical anthropology. Physical anthropology, distinct from evolutionary biology, examines the biological and evolutionary history of humanity. The study of leprosy in the fossil record specifically can provide extraordinarily descriptive analysis and extrapolated assessment of the biological origins of the disease, and its relationship to mankind. Because leprosy is primarily a disease of the nervous system, its lack of organic remnants in the fossil record has constrained significant research. However the secondary infections associated with the deformed extremities have distinct osteological patterns and morphologies, and in turn can be seen in skeletal remains (Manchester 1999).

The osteological injuries, seen in the skeletal remains of those with leprosy, result from the direct pathogenic activity of two specific bacterial agents. The least common osseous lesion is a small, spherical cortical or subcortical erosion of the limbs or oronasal floor (the region above the soft palate of the mouth) (Ortner 1999). In the fossil record, it is circumstantially presumed that morphological remnants of these corrosions are the result of *M. leprae*’s granulomatous lesions, although this is unconfirmed in clinical contexts. A more common clinical and skeletal manifestation of leprosy is inflammatory lesions in the peripheral bones and joints, as well as in the oronasal cavity. Although these lesions may exist in non-leprous individuals, it is the physical distribution of the marks on the skeleton that suggest the clinical presence of the disease. That being noted, most of the knowledge gained about skeletal remnants of leprosy, a bacterial condition, is through differential ontological diagnoses.
Within the two large osseous bacterial categories, the specific pathological features know to be associated with leprosy can be examined. Along the nasal floor, distinctive erosive pits, thought to be remnants of granulomatous lesions, can be seen with osteoblastic (remodeling) activity. It is thought the presence of granuloma lesions result in heightened osteoclastic (derogative) absorption and the high oxygen saturation, itself a feature of inflammation associated with the neuropathy (nerve damage) of HD, constructs much of the visible morphological evidence. Immediately preceding the degradation of the bone, osteoblastic activity creates new ‘woven’ bone at the site. This ‘woven’ bone is responsible for the rounded and smooth appearance of the nasal cavity of an individual with leprosy. This smoothing of the cortical surface is frequently noted as a striking paleopathological clue to the presence of HD (Ortner 1999).

The unique skeletal structure of the hands and feet are perhaps the most easily recognizable and diagnosable feature of skeletal leprosy. Within the metatarsals and phalanges, small osteomyelitic lesions, or holes, can develop from direct bacterial invasion and proliferation. In a modern clinical context independent of HD, such injuries are not located in the foot or hand, but along the shaft of the tibia and femur, and other larger bones. Pitting and other porous morphological changes characteristic of inflammatory infections are visible in metatarsals and metacarpals, as well as in the nasal aperture of leprosy patients. These characteristics offer a route for the differential diagnosis of leprosy in a skeleton.

As the ability to recognize the key osteological signs of leprosy, as well as other bone-related diseases, improved so did the accuracy and degrees of confidence in differential diagnoses of paleopathologic specimens. These skeletons, if found in regions
associated with the texts, gave support to the statements and allusions made in ancient writings to leprosy as being genuine to our understandings of the disease, and not a fault of mal-translation or transliteration. However, until very recently, the oldest confirmed skeletal evidence of leprosy was found just outside of Jerusalem, and dated to only about 1 C.E.

And then, in 2009, a discovery was reported that made scientific headlines. The remains of a middle-aged man were found within a large cement burial box. Radiocarbon dating of the stratified layers of the excavation site, located 40 km outside of Udaipur, Rajasthan, India, suggested the man was buried between 2500-2000 B.C.E. The burial practice and reconstructed dietary projection supported the radiocarbon dating evidence of the time period. Initially the man, named Individual 1997-1, was examined and described using standard macroscopic bioarcheological techniques. Sex and age were determined using the remains of the pelvis. The individual was found with a fairly complete skull, but with a fragmentary post-cranial skeleton (Robbins 2009).

But what researchers found along the nasal aperture, pitting and ‘woven’ bone seen primarily in skeletons of those with leprosy, pushed back the established fossil record of this disease by almost 2000 years, 500 years before the first textual mention of the disease by the Ebers Papyrus. Although some cautioned the claims as premature, the Balathal skeleton, individual 1997-1’s new name, does show clear evidence of rhinomaxillary syndrome, (the smoothed bone and pitted floor of the nasal aperture), a key diagnostic feature of leprosy (Robbins 2009). The researchers affirm their evidence was clear: leprosy has been a player in human history longer than ever thought.
In addition the excitement of the oldest suspected evidence confirming leprosy’s presence in the mid South Indian Neolithic period, the Balathal skeleton is perhaps the earliest example of funerary ritual using the ash of cow dung, a practice integral in later rites of burial in the region. Ashmounds, large mounded structures made of layers of cow dung and cultural artifacts, are littered over the Indian peninsula (Johansson 2009).

The purpose and origins of these structures remains a point of debate amongst archeologists and anthropologists. This encasement of the Balathal skeleton in the large cement-like box could also be indicative of the well document later Vedic tradition (1500 – 500 BCE) of burying those with leprosy alive. It is very rare to find funerary skeletons of men from this time period, as most, the ancient texts informs us, were cremated in ceremonial rituals to honor the gods.

In later Vedic tradition, those with leprosy were not deemed suitable sacrifices, and their bodies were, in turn were buried alive in the earth in order so that they would not travel and spread the disease to those with whom the come in contact (Cambell 1869). Although the highly speculative nature of assigning meaning and defined cultural logics to the remains of the Batathal skeleton may only produce more questions than the find itself is capable of answering, this is an incredible discovery that can perhaps offer insights to the biological map of the progression of humans, societies, and disease across the Old World.
Early Narratives of Leprosy

Through the height of the Colonial period, adventure and romance were synonymous with one place: Egypt. Empires flocked to the fertile banks of the Nile to claim for themselves, often by force, the secrets of the ancient world, forgotten in the sands. In 1873 in Thebes, German Egyptologist Georg Ebers obtained several such papyrus scrolls. Little did Ebers know, these bits of pithy stems, marked thick script, would shape modern understandings of disease and medicine in ancient Egypt. The longest scroll, now known as the Ebers Papyrus, chronicles remedies for maladies from breast cancer to dental cavities and dates to about 1,500 B.C.E, though it is thought the therapies described were copied from a series of books many centuries older (Bryan 1931). It is within these pages, almost perfectly preserved for 3,500 years, that the first textual reference to what we understand to be leprosy exists.

In the chapter, ‘diseases of the skin’, the papyrus reads, “to remedy ukhedu (translated from Ancient Egyptian to mean leprous) spots on the skin, cooked onions, sea salt, urine. Anoint to marks” (96-96). It is clear from the plain description, the social implications of this disease are not a defining influence over the condition itself. Nowhere in the text does it make moral or relativistic judgments about leprosy. Several passages and remedies to other ailments invoke prayer to influence and aide healing, but such methods are absent from the entry for leprosy, indicating perhaps the physicality of the disease, and not the stigmatizing moral distinctions so common later (96-98).

It is not until 300 BCE, does the Egyptian historian Manetho, living in a Ptolemaic Egypt, suggest in his work, Aegyptiaca, that the Hebrew people were banished
from Egypt specifically because the prophet Moses was ‘a leper’ (Safrai 1981). Yet, the impassive assessments of the physicality of the disease in the Ebers Papyrus greatly contradict other ancient sources from which many colloquially derive their knowledge.

**The Treatment of Leprosy in Ancient India**

Chaulmoogra oil, derived from seeds of large trees of the *Hydnocarpus* genus, has been used in Indian and Chinese traditional medicine, both for the treatment of leprosy, for thousands of years, and remained the primary form of treatment until the advent of sulphone therapy in the mid 20th century (Dogra 2013). The anti-bacterial characteristics of this oil yield some success in treating dermatological infections. Use of the oil in the wound dressings of trophic ulcers is shown to improve healing outcomes (Ganguli 2001).

The integration of Chaulmoogra oil into the medicalized lexicon of western empiricism only occurred in 1854 when description of the anti-leprotic properties of the topical oil amongst traditional healers, and was institutionally introduced into the treatments offered by the Madras Leper Hospital in 1874 (Parascandola 2003). At the Louisiana Leper Home at Carville, Chaulmoogra oil was administered orally to patients as standard treatment beginning in 1901.

By 1916, the outcomes of all Carville’s 170 residents treated with Chaulmoogra oil showed the therapy to be effective only against less advanced stages of the disease. To avoid nauseating side effects, a method of injecting the oil subcutaneously was developed and widely adopted in colonialized endemic health systems. Hyper-medicalized, Chaulmoogra was the leading treatment of HD within Colonial India’s medical infrastructure, both without consent and often to the detriment of the patients, until...
sulphone biochemotherapy all but eliminated the therapeutic agent from the medical discourse (Parascandola 2003).

However, the use of topical Chaulmoogra oil, as well as oral therapies and intravenous therapies, are very important aspects of self-care rituals for almost all of the residents with whom I interviewed. It was during these periods of ritualized self-care with donated medical supplied and purchased Chaulmoogra oil; residents cleaned and dressed wounds sustained from daily tasks.
Part III: The Living Leper

“Okay, sir, my final offer: half a shekel for an old ex-leper?

Did you say ‘ex-leper’?

That’s right sir, 16 years behind a veil and proud of it, sir

Well, what happened?

Oh, cured, sir.

Cured?

Yes sir, bloody miracle, sir. Bless you!

Who cured you?

Jesus did, sir. I was hopping along, minding my own business, and all of the sudden, up he comes, cures me! One minute I’m a leper with a trade, next minute my livelihood’s gone. Now so much as a by-your-leave! ‘You’re cured, mate.’ Bloody do-gooder.”

-Monty Python’s “Life of Brian”

Exported Meaning

This scene from Monty Python’s Life of Brian enforces understandings of many citizens of the Global North to practical manifestations of leprosy as a relic of the past. However both the disease and the illness are present in modern society. Historical and folk narratives suggest socialized leprosy has been present in the human pathogenic profile for thousands of years. Recent genetic analysis suggests its origins, reductively evolving from a TB ancestor, to have occurred in South East Asia (Grimm 2005).

From this molecular and evolutionary perspective of disease, we shift our focus to the variations of human understandings thereof. The disease state of being is
metaphorically constructed as an entity in opposition to the Self (White 2009). The division of disease and health allows for the commodification of the latter by scientific knowledge-based exploration of the former, and thereby institutionally imbuing WBM as agents of Foucault’s biopower. These constructions of meaning radiate as far as the subjugating actors extend.

The exportation of these Western understandings of the duality of disease and Self are reinforced through the institutionalized systems of governance, economy, and society in the wake of globalized colonialism. These models are shifted and altered to exist simultaneously with folk health understandings within the collective social conscious of the region (Pels 1997). Continued cultural saturation through technology and media reinforce and refine these positions.

Access to knowledge regarding empirical explanatory models, though institutionally unavailable to many, is becoming increasingly available through cyber exchange platforms. In this capacity, Western medical reductionism, culturally contextualized and derived from biopolitical and sociocultural historical occurrences of the Western anthropological narrative, is exported to formerly colonialized nations with unique cultural and historical contexts under the assumed authority of modernization and development (Sivakumar 2012).
Stigma and Sin

In order to understand the socialized and institutional relationship of leprosy stigma to sin in India, one must first understand the metaphor of leprosy sin itself. The denotation of sin is inherently a moralizing instrument used to reinforce socially normative understandings of right and wrong.

Theologians are quick to define sin as the opposition of an autonomous entity, whether that be in nature, disposition, or actions, to the defined and interpreted law of God. This understanding is supported through biblical and other doctrines in the Western and Eastern religious traditions. Within this understanding, ‘sin’ is not so much a moralistic opposition to the specific will of a omnipresent creator, but is a demarcation of an Othering agent and thereby a usurpation of personal autonomy to the collective will of those with social power (Jensen 2011). This understanding of the impact of an association between the disease and sin inform folk perspectives of the nature and meaning of pathogenesis. It is from this insidious symbolic nature of leprosy and sin, thus grouping individuals with the disease in a separate identity category than Self, its constructed stigma originates.

Leprosy’s stigma is an integral construct of the human drama, aiding in the shaping of religions, societies, and human cultures. However, its historical presence, and the misinformation thereby associated, overshadows not only its continued existence in society, but also the cultural and public health problems its existence both illuminates and perpetuates. Under the burden of its history, marginalized populations of the
impoverished and forgotten suffer though a stigma far more insidious than the disease itself.

The 20th century sociologist, Erving Goffman, defined stigma as the shared identification of a person or group of people based upon some physical, behavioral, or social trait that is perceived as being different from the group norm (Goffman 1963). Within this framework, stigma catalyzes the process by which individuals are disqualified from memberships within patrimonially constructed social groups and the sociopolitical and socioeconomic privileges thereby granted. This application of stigma intensifies when seen through the framework of a society with historically rigid sociocultural boundaries, such as India’s caste system. Within the power differentials of this stratified society, the stigmatizing agent of leprosy transcends social castes and creates a marginalized society of ‘others’ abandoned by traditional kin relations.

And yet within these communities in the therapeutic landscape of the leprosy colony, I viewed constructed kinship structures formed and maintained, creating socialized sanctuary and modest independence despite their exclusion from society at large. In addition to this historic and culturally reinforced segregation of those with HD from society, the WHO’s 2005 announcement that based upon reported disease prevalence, leprosy was eliminated from India (WHO 2005).

As I toured the Taj Mahal, a symbol of the grand antiquity of India, the guide showed me a building off of the main road. The guide, an educated member of a tourist-based industry, told me the Hospital used to be one of the main hospitals for the treatment of Leprosy in Northern India. I asked him if the building was still used for the same purpose. He shook his head and laughed. He told me that because of better health and
sanitation because of education and development initiatives, leprosy was no longer
around. This association of leprosy being a sign of pre-modernity reinforces the distorted
and dogmatic pathogenic origins of the stigma itself.

**Illness, Sin and Christianity**

Leprosy has been present in human society for an estimated 4000 years (Robbins
2009), and is referred to frequently in historical and religious texts. Shown in the book of
Leviticus, a person with suspected leprosy is condemned to “…remain unclean as long as
he has the disease. He is unclean. He shall live alone. His dwelling shall be outside the
camp” (Leviticus 13:46). From its pathogenic origins, the marred and disfigured
caricature of the disease has stigmatized its sufferers beyond all other ailments, and is
used as a comparative marker for modern pilloried diseases such as HIV/AIDS, for
example, “AIDS: The Twentieth-Century Leprosy” (Sainsbury 1992: 68). And leprosy in
the Judeo-Christian tradition, both the social condition and the pathological disorder, is
vilified and stigmatized as a direct mark of sign and impurity.
Chapters 13 and 14 of Leviticus, contemporaneously dating to the Ebers Papyrus, state, “and the priest shall look on the plague in the skin of the flesh: and [when] the hair in the plague is turned white, and the plague in sight [be] deeper than the skin of his flesh, it [is] a plague of leprosy: and the priest shall look on him, and pronounce him unclean”. But beyond the physical manifestation of the disease, the social implications, as detailed in the chapter, reinforced an understanding of the sin of the sufferer’s existence hitherto unseen in the textual record. It states, “and the leper in whom the plague [is], his clothes shall be rent (a sign of mourning), and his head bare, and he shall put a covering upon his upper lip, and shall cry, Unclean, unclean for all to know” (Leviticus 13: 45-48). This construct of leprosy as both a disease of the body and of the soul is credited with the analogous paradigms in medieval Christendom, and later in predominately Judeo-Christian ‘Modern’ societies, and only deescalated in the collective conscious of the Global North as the prevalence of the disease dwindled.
And indeed, it is from the representations of leprosy in both testaments of the Bible that many draw their misguided understandings of the pathology of the disease and the plague-like descriptions of those suffering are serialized and vilified. These descriptions are thought to play a major influence in the modern understanding of what leprosy actually is, as well as reaffirm the presumed ancientness of the disease (Browne 1970). In fact, many in the Global North go so far as to presume the disease exists nowhere but in the minds of biblical scholars and historians. It is of note to suggest there is some contention between scholars regarding the merit of the transliteration of the word leprosy, as opposed to just its translation. For example, leprosy as referred to in the bible could be used as a blanket term for all dermatological conditions, leprosy being one among them (White 2009).

As influential as this disease has been throughout history, early screening and preventative measures has made it increasingly rare in the Global North. Its lack of prevalence in these areas has pushed the disease to almost mythical status confined to the text of the Bible and other moralized associative references.

The biosocial illness of leprosy is viewed by many religious organizations as a metaphor for not only the inherent sin of man, but also the healing and redemptive promise of salvation through faith. Nowhere is this illustrative devise more ubiquitously used across religions than in the context of leprosy. This view is reinforced through religious teachings inside and outside of the pulpit. Through the pages and allegories of the King James Bible, a popular English translation of the ancient texts, leprosy has been transcribed across millennia 37 separate instances in both the Torah and the New Testament.
To those living during the 1000 years of the middle ages, leprosy was not just a
disease of the body, it was a constant reminder of the precarious relationship between
life, death, and eternal salvation. It is unknown when the disease first entered the British
Iles, however by the 4th century, its presence has been noted in various parish records and
administrative proceedings. By 1050, it was endemic to the land (Brody 1973).

The social structure of society during this time centered on the Church, of which
even the king was subject. This hierarchy promised salvation to those whom operated
within the framework of the churches teachings, and banished to the fierily pits of eternal
agony those who opposed this construct. The superimposition of political and religious
institutions removed distinctions between corporal and spiritual existence, creating in its
wake a hybridized understanding of the interconnectivity of physical ailments and moral
impunities. The fate of the spiritual soul therefore took precedent over the fate of the
corporal being, and the presence and fate of certain communicable diseases, such as
leprosy, became not a reflection of a physical infection or occurrence, but the divine
salvation of ones soul (Brody 1973). And yet, although used as a metaphor for divine
salvation, leprosy achieved a dualism in the collective cultural conscious in that it was
simultaneously loathed and lauded. This is seen in this hand account of their treatment:

“[sic.] men already dead except to sin; often dumb, with festering bodies whose
insensible limbs rotted off them; heartbreaking and horrifying spectacles of human ruin;
objects of repugnance and terror; driven from the house, the marketplace, the village, and
the fountain; persecuted even by their parents; disfigured, unrecognizable, identified only
by their names; avoided, shrunk from, detested, despised by relatives, fathers, mothers,
spouses, children; wandering night and day, naked, destitute, exposing their
loathsomeness to the gaze of passers-by to move them and obtain alms.” (Quoted in
Brody 1974)
Translated from Ecclesiastical Latin, these are the words of St. Gregory of Nazianzus spoken during a funerary sermon in 379 CE. This oration articulates the anxieties of a society damned by mortality and saved through everlasting life through the mercy of intangible perfection, and by extension, through will of those sent to do his work. The take away message presents a contradiction in congregational opinion. Once diagnosed, the leper is presented as a socially dichotomous entity that both demands fear and deserves pity, mirroring their status as ‘Others’. Within this context, the integral yet independent threads of biological conditions and social structures inform lived realities for individuals defined as leprous. This sermon articulates culturally understood realities of leprosy in the ancient Christian conscious.

St. Gregory of Nysse (332-400), a significant contributor to the Nicene Creed, or the digested belief mantra of Christianity, paused during his explanation of the physical trauma of the disease, and spoke about the psychosocial stigmatization and isolation and of the ‘Others’. He states,

“They have no friends but each other, united as they are in misery; that which makes them despised of other unites them in a close bond among themselves; repulsed on all sides, they become by their union a people in themselves… Are they not excluded from public assemblies and feast days like murderers, parricides, fated to be perpetual exiles, and even more unhappy than these! For murderers are at least permitted to live with other men; these are driven away like enemies. They are denied the same roof, the same table, the same utensils with others. Moreover they are barred from the cleansing waters for public usage, and there is fear that even the rivers may be infected with their malady. If a dog should lap up water with a wounded tongue, we should not consider the water to have been contaminated by the brute; but let one of these afflicted ones approach it and we believe the water is rendered impure by this human being.” (Quoted in Brody 1974)

This view is reinforced through religious teachings inside and outside of the pulpit. Through the pages and allegories of the King James Bible, a popular English
translation of the ancient texts, leprosy is mentioned in 37 separate instances in both the Torah and the New Testament.

In the Torah, or the foundational scriptures of the Judeo-Christian religious traditions, Leprosy is depicted as a physical representation of sin and evil. Those who suffered from the condition were therefore identified as ‘unclean’ and were removed from the community. The text states, “[w]hen a man shall have in the skin of his flesh a rising, a scab, or bright spot… like the plague of leprosy; the he shall be brought unto the priest… and the priest shall look on him, and pronounce him unclean.” (Lev. 13:2-3).

The significance of cleanliness, the Priest surmised, suggested purity of body, mind, and soul were needed to enter Heaven. In this passage, not only is leprosy identified as a sign of moral impurity, and moral sin, but also the designation of who is leprous is left not to medical professionals or healers, but to the will of the congregation based upon identifiable and visible signs of illness. In this capacity, the dualistic biological and cultural faces of the disease, as well an example of socialized biopower through cultural identification of Self and Other informing biomedical and lived realities, informs socialized understandings of the modern illness.

Leprosy as a metaphor undergoes transformations from it’s designation as a moral impurity unworthy of normal social interactions, to a symbolic tool by which to demonstrate the saving and healing powers of Jesus Christ and the cultural construct of Religious authority. And it is from the traditions and institutions of the Catholic Church I learned of the social illness long before I learned about the disease.
At the turn of the last millennium, two conflicting agents dictated subjugation of the proto-proletariat: politics and religion. Religion is a system of symbols manufactured, embellished, and replicated by men in order to both contextualize existence and instill a lasting form of social control on society as a whole. From this corporal understanding of religion, a ubiquitous template of the biopolitical relationship between religious superstructures, not spirituality itself, and the individual can be identified (Geertz 1994). The specific tool used by these religious structures to enforce this hierarchical relationship is through the morally relativizing agent of sin.

From a similar vein, the application of Foucault’s social theories about the control of populations illuminates similar relationship in the structure between the individual and the political state.

The separation of spiritual power and political power is a uniquely post-reformation understanding prevalent in the Global North. However, attempts to fully integrate these non-autonomous agents lead to the prioni understanding of the use of spiritual power as a proxy and tool for the achievement of political power, and vise versa, the use of political power for the achievement of spiritual power (Brody 1974). Examples of this fluid duality of achievement are presented through the infamous politicking of the upper echelons of the Holy See. However this top-down understanding of the separate influencing agents of power only yield perspectives relating to the structural control, and do little to shed light upon the effects of that power upon the subjugated populations.
To a peasant living a subsistence existence, the interconnectivity between politics and religion does not alter the presence of a relationship between the person and the power superstructure; only modifies circumstances of that relationship.

The biosocial disease of leprosy is viewed by many religious organizations as a metaphor for not only the inherent sin of man or sin across lifetimes, but also the healing and redemptive promise of salvation through faith. Nowhere is this illustrative device more ubiquitously used across religions than in the context of leprosy.

Historically, it has been suggested those with leprosy were marginalized from ancient Indian Society for several reasons: the chronic and potentially disfiguring of the disease, inconsistently effective therapy, and its association with sin (Jacob and France-Paredes 2008). This stigmatic framework presents a historical buttress by which to interpret modern regional understandings of the disease.

Contemporary to the fossilized findings, early Hindu works are used to understand the origins of culturally specific logics and symbols applied to the biosocial illnesses. And the oldest suspected textual evidence of leprosy is found in these works. These laws explicitly limit the contact of those socially identified as ill with the outside world. They also introduce and reinforce social understandings of the disease being heritable; impacting not only the individual but also the social positioning of those related to the individual. These laws also punished other members of society who agreed to enter socially constructed marriages and kinship agreements with the families of an individual with leprosy. This punishment through social ostracization was rationalized as the illness was seen as divine punishment for sins committed in a past life (Jacobs 2008)(Buhler G 1886).
This cultural construct of the origins of leprosy historically removed all forms of social agency of a person based upon the presentation of a biological entity, regardless of caste or social positioning within society. Understandings of pathogenesis, informed by sins in a past life, implies social understandings of a soul or character based flaw being a contributing factor to the presentation of the disease, instead of a physical properties based in structural and social inequality.

**Leprosy in Ancient Indian Society**

India is a vast country with a distinguished and cosmopolitan historical narrative. Bordered to the south by the Indian Ocean and to the north by the Himalayan Mountain Range, India has distinct national narrative and is the origin of four major world religions: Hinduism, Buddhism, Jainism, and Sikhism, with Christianity, Judaism, and Islam arriving along the ancient trade routes by the 1st century (Stein 1998). Its position as a major trade hub and sociocultural crossroads presented a unique epidemiological and sociocultural landscape of the meeting of East and West.

In conjunction with the paleoanthropological evidence discussed above, India is thought to be the origin of leprosy, with skeletal evidence dating to 2000 BCE. The pathogen was then thought to spread to the reaches of the united ancient world from the Indian subcontinent through trade and war. The long incubation period of the pathogen supports such a transmission scenario (Jacobs 2008).

Long known through descriptions in holy books, the oldest suspected textual evidence of leprosy is found in the sacred Hindu works, the *Atharava Veda*, as well as the
Laws of Manu. One of the four pillar texts of Hinduism, the Atharava Veda is dated to approximately 2000 BCE, and the laws themselves are dated to 1500 BCE (Jacob and Franco-Paredes 2008). Within these texts, leprosy is described in a familiar and stigmatizing fashion. Book one, chapters 23 and 24 titled, “leprosy cured by a dark plant”, state a reaction to the disease in less than impassive terms, and equates the presence of leprosy with, “the white mark begotten of corruption”. The social laws outlines in these documents not only prohibit contact with those known to have leprosy, but also punish the those who marry into families of lepers, summarily ostracizing and condemning those associated with the disease, as biophysical and psychosocial agents of sin.

Perhaps the best indication of the sociocultural origins of understandings of leprosy in ancient India come from an allegory in which leprosy is cause of a king’s fall from social power. This allegory illustrates the humbling and undiscerning influence of leprosy through the end of this historical period. The disease had the power to renege social positions and expel any member of a community, from pauper to king (Skinsnes 1973).

Leprosy is symbolically equated with loss of social position as well as communal expulsion, regardless of social cast or earthly status. Ancient marginalization of those with leprosy is not unique in the social history of the illness and several factors contributed to this trend. The disease is chronic, potentially disfiguring, and has inconsistent or no therapy of any substantial effects. The illness also is culturally reinforced as a metaphor for naturalized sin. This, coupled with a fear of contagion, left a
lasting sociocultural stigma surrounding the disease in the institutionally Hindu society that informs contemporary self-understandings of the disease.

“Why [did] God do this to me?” The President of the colony asked me. He was a 39-year-old man with a second grade education who was first diagnosed at the age of 16, after being incorrectly treated for dehydration. He was abandoned by his extended family and his wife because of the illness, and devoid of kinship structures integral in Indian construction and conception of self, he viewed the disease as a punishment for something he must have done in a previous life.

As he lost fingers and toes through secondary infection in numb limbs, he slowly lost the ability to work and support himself in any other capacity besides begging. And so he wandered to the major city Dehradun, as did others in the colony, in search of treatment and a place to stay. And once directed to the colony by those as the hospital, the agency of independent living yielded the constructed communal kinship structures based upon shared biocultural experiences and independent of the rigid social stratum of society outside the therapeutic landscape of the leprosy colony.

**Constructing the Caste System and Kinship**

Inherent in an anthropological examination of India is the discussion of the unique and historical social construction of the Caste System. The Caste System is a name given to the socialized positioning of traditional Hindu societies. It is a complex social and religious matrix based upon heredity, spirituality, social identity, and power and is the primary socialized distinction of kinship.
The highest caste is the Brahmin caste, which consists of those engaged in scriptural education and teaching, essential for the continuation of knowledge. The Kshatriya take on all forms of public service, including administration, maintenance of law and order, and defense. The Vaishyas engage in commercial activity as business. The Kshudras work as semi-skilled and unskilled laborers. Finally there are the Dalit, or the untouchables. These constructions are based in religious ideologies of a spiritually and socially segregated society.

![Diagram of the Hindu caste system]

Figure 2: Modeled institutionalized cultural power structure of the Indian and Hindu caste system.

And although significant social and institutional initiatives to desegregate the social stratum of Indian society have been implemented in recent years, the informed cultural implications of the system are still present in the extended cultural narrative.
following is an example of the internalized logics of stratification of individuals based upon social structures still playing a role in the construct of modern Indian identity and society, as exemplified in the 2007 documentary by Indian filmmaker, Stalin Kurup, India Untouched: Darker Side of India.

"Caste [system] is not a discriminatory system, though you claim it is.”

A Brahman priest replied to the leading questions of the foreign film crew,

““This is a purely scientific system and it is in the interest of society. This system leads to the betterment of society. I can meditate for four hours but you will find that difficult. I will find it difficult to do what you are doing now. The Varna (caste) system is in place since a long time. If you believe in the truth of our Shastras, Vedas and Unpanishads (Holy books of the Hindu religion) then you have to believe in the caste system too. You must believe in it. A tradition that goes on for generations gets into the blood. For example, you don't need to teach a fish to swim. Similarly, you see that a barber's child has an in-built art to cut hair." (India Untouched, 2007)

This understanding of the roles social castes and kinship structures play historically divisionary practices contextualizes them. It is from this contextualization that socially stigmatized arguments and understandings of leprosy are propagated through the culturally authoritative lens of modernity. The priest connects symbols of Western modernity, such as a claiming the system was ‘scientific’ and based upon heritable biological realities, to explain and rationalize the logics of cultural symbols.

The existence of historical kinship markers related to social positioning play a key role in the understanding of Self and Other in Indian society, and yet in the colony, the shared socialized experience of leprosy transcend these traditional kinship lines to forge modern and self-actualized communities, despite being viewed as ‘pre-modern’ by the urbanized and educated populations.
A Colony within a Colony- Leprosy in British India

Under the social theory of the ‘white mans burden’, and its subsequent sociopolitical exportations, Western Empiricism and the medical systems thereof was exported and institutionally reinforced in the occupied world, including the Indian subcontinent. This outflow, institutionalization, and modern maintenance of Western specific systems of sociomedical methodology has yielded a unique biocultural milieu of folk and Western understandings of relationships of biological disease and cultural illness.

Flush with cash and the need for natural resources due to the overwhelming success of the Industrial Revolution, the Great Britain is perhaps one of the most notorious imperial agents of the 19th century. The Age of Empires, as it is called in western history textbooks, saw with it an explosion of global socioeconomic exchanges, but at the expense of individual autonomy and political sovereignty of the subjugated populations (Kakar 1996).

The social consequences of imperialism are well discussed. The sociopolitical movement yields to, “…the larger part of mankind [being] subservient to the other, and during which millions of innocent human beings have had their resources plundered and their institutions and beliefs destroyed whilst they themselves were ruthlessly killed, thrown into bondage, and contaminated by diseases they were unable to resist” (Levi-Strauss 1966:126). As it is so colorfully painted above, this rapid globalization and colonization created a milieu in which contact between previously isolated
epidemiological communities exchanged pathogens and disease. Nowhere is this colonial trend more apparent than in the context of British India (Kakar 1996).

Through economic and political control of the British Empire over the Indian subcontinent, often gained by coercion and brutality, Western understandings and cultural practices permeated the colonized cultural belief systems. This created in its wake a power hierarchy in which occidental understandings of culture, society and medicine were institutionalized favored to traditional understandings thereof (Raghuramaraja 2011).

The relative social equality granted by the colonial power structure through the appropriation of cultural morays made the adaption of British cultural symbols and identities an agent for social mobility. From this, the cultural appropriation of the collective English conscious, including view on leprosy informed by the medieval relationship to the disease, dispersed through the whole of Indian colonial society, and not just amongst the powerful elite. It is from these frameworks, institutionalized treatment of HD as a highly contagious biological pathogen, the falsely understood socialized reality, shaped the modern Indian conscious (Raghuramaraja 2011).

**Leprosy and Modernity in Post-Colonial India**

After the Indian Independence Movement of 1947, the post-colonial government instituted a National Leprosy Control Program that focused on disease control and surveillance. After curative multi-drug therapy was introduced at no cost to the Indian people in 1983, the government shifted their leprosy efforts from surveillance to elimination (Arole 2002). These campaigns, beginning in 1997, included knowledge
dissemination, house-to-house searches, and awareness programs using popular media and education initiatives. In addition to this de-stigmatization campaigns, the Indian government integrated leprosy care into their state health system. These interventions have centered on westernized understandings of disease and illness, and have spent little time addressing the numerous non-allopathic treatment strategies in India. This lack of sociocultural previsions for the understanding of a disease has contributed to its limited successful use of its initiatives (Nicholls 2005).

Although the Caste system and Colonial superstructures informative of Indian the collective understandings of leprosy have been institutionally abolished, the stigmatization of leprosy is deeply ingrained within the Indian social system, partially due to a lack of de-stigmatizing knowledge (Jacobs 2008). Socially marginalized groups, such as women, institutionally defined minority social and ethnic groups, and the urban poor are much less likely to seek care at the first signs of the pathogen for fear of the socially desiccating illness, and understand institutionalized relief and treatment initiatives as being unable to account for individuated and contextualized understandings of the disease (Staples 2008).

When examining leprosy within the nationalized context of modern India, the understandings of modernity itself comes into question. Discourses of modernity have traditionally been through the lens of western philosophy. This approach is incompatible when assessing modernity in India, where understandings thereof are informed by the country’s colonial legacy. In his work, *Modernity in Indian Social Theory*, philosopher A. Raghuramaraju describes the result of imported understandings of modernity by stating,
“India is a good example of a society that is neither pre-modern nor distinctly modern’;
India is a place where ‘modernity has to reckon with pre-modern’ (Raghuramaraju 2008).

With the appearance of the constructed identity of modernity, understandings of identity and Self shifted to include discourses of nationalism. The construct of the ‘nation’ as an independent cultural entity is not present in Indian sociocultural discourse before colonization. And yet, this concept of nationalism and national unity is reinforced in the education system. I experienced this instillation of nationalism when I interacted with the students and the teachers of the KHEL managed L. Devi Academy (LDA).

“We always tell them,” the English teacher, Ms. Stevens, told me when the children were running and yelling on the playing field, “they must stay in India. They must not go overseas. We need good and educated men and women here, to modernize the country and make it strong.”

Yet symbolic meanings and cultural stigma unify individuals whose identities are informed by modernist and traditional understandings. The social theorist, D. L. Sheth suggests, “These numerous entities, however, do not live in insolation, nor do they enjoy complete autonomy vis-à-vis each other. They share a symbolic meaning system, which ensures fluidity of cultural expression among them at different levels (Sheth cited in Raghuramaraju, 2011). And it is through the shared symbolic stigmas of leprosy, can a meta-stigmatization event, or a stigmatization of a construct of a stigmatization, take place.
Conclusions:

Ethnographic Meaning and Modernity

Classroom Constructions of Modernity

Students of LDA and Ms. Stevens (The English Teacher) responding to the question, “Who is going to work hard and go to college?”

Within the power differentials of India’s traditionally stratified society, modernity, particularly through education, offers an equalizing agent to those born into culturally and institutionally stigmatized social castes to achieve social equality and cultural de-subjugation. This understanding of modernity through education was reinforced through the classrooms of LDA.

One morning my mother who was visiting me asked the children of the 4th and 5th grades what they wanted to be when they grew up. It was a common question when I was that age, as it is today, and the children, one by one, stood and said that he or she wanted
to be a doctor, and a pilot, and a dancer. The children of LDA are from the poorest socioeconomic classes of the city, and many of them have parents or grandparents who live in the leprosy colonies. It was clear from conversations with the students and with the teachers that the children has been institutionally taught to equate the modernized understandings of social success with educational achievements.

Had these children not been in such an educational setting run by KHEL, constructing identities in the minds of their students of the necessity of a ‘Modernized’ India, their professional aspirations would be limited to those accessible to members of their sociopolitical society. Educationally acculturated with notions of contextualized modernity and national pride, these new generations of future urban professionals are members the growing educated class of socially mobile modern Indian culture.

**Making Meaning**

“It’s like they are trapped in the past, with an disease of a different world,” I read in some of my early ethnographic notes describing the interactions between my interpreter, Pugwat, and the President of the Colony, “Pugwat, repeatedly told me not to touch them or anything because they are ‘dirty’.”

The warning of the ‘dirtiness’ of the residents of the colony was repeated to me wherever I went. When I pressed why these residents were seen as dirty, Pugwat explained,

“It’s very dirty, they are very dirty. They may still have [leprosy]. They don’t know any better. They were poor and had no education. They are very superstitious, I think the disease is a sin from god.”
Pugwat described himself as a member of the growing lower-middle class of Indian society. This economic class is constructed of historically impoverished populations, educated and able to achieve some social agency from the institutional equalizing associated with Modernity. During our interactions, he described a dichotomy between the religious biocultural constructs informed by folk logics and scientific biocultural constructs informed through Modern education. Yet, in doing so, he contextualizes and rationalizes a social stigma of anything ‘anti-modern’ using biocultural understandings of pathogenesis, and not only biological ones.

By identifying these applied categories of understanding, Pugwat describes a social divide between the colony residents and himself. The former were ‘anti-modernity’ based upon their folk understandings of the pathogenesis of leprosy as a punishment for a sin in a past life, where his constructed Self and identity represents Modern empiricism. This fosters a meta-stigmatization where the symbolic stigma of leprosy is itself a symbol of ‘anti-modernity’, and thus is institutionally stigmatized through the Modernized educational systems.

This symbolic string of stigmatizing those with leprosy yields to the immediately association ‘anti-modernity’ with leprosy. Understandings of leprosy in the context of it’s relationship to the modernizing city of Dehradun and the both metaphors of sin and redemption, shed light into the construction of individual identity within the socialized construct of the past.

And yet, it is the very stigma of the illness, coupled with biologically long incubation periods, which reinforce a lack of treatment-seeking behavior at the
dermatological signs of the disease. A patient with whom I spoke illustrated this cycle with his story, translated into English from Hindi by Pugwat:

“I first noticed a rash on my arm that looked like a circle. I was about 22 and had a family and was getting a job as a teacher. I went to a doctor and he told me it was leprosy. I didn’t know why it happened to me.”

I asked him why he thought he got the disease. P shook his head and smiled.

“He doesn’t know,” Pugwat explained to me without translating my question, “he thinks it was a sin against God.”

The man continued his story.

“And then I got a job as a teacher in a different village and I went.”

I asked the man if he found a new doctor when he got to the new village. He told me he had not. He had just been married and had not even told his new bride about his diagnosis.

“The mark went away,” he explained, “and I kind of forgot about it.”

He told me that for years he taught, before he gradually began to lose feeling in his hands and feet. It was becoming difficult to stand all day and to use the chalk. I asked him if he told the school at which he worked about his troubles.

“No,” he said, “I hadn’t told anyone. If they knew I had leprosy, they would have fired me. It was a good job, so no, nobody knew.”

I asked him how he went from teaching to living at the Colony and he told me that finally someone told the head master that he had leprosy and he was fired. His wife left him and he went to Dehradun to be treated at the hospital. After he was declared cured, he came to live at the colony.
I asked him if he was still a teacher. He shook his head and said he only begged like the others. Begging was the primary form of income for the residents of the colony. Many residents have difficulty doing manual labor and textile work because of the disease, and so begging is the only remaining source of income for them. A local charity donated a candle-making machine to the colony so the residents did not have to beg, however, Pugwat explained, “no one wants to buy candles from people with leprosy. They may be dirty. They will be afraid they might catch leprosy too.”

Just then I heard deep thuds radiate through the corrugated tin roof. I watched as rocks bounced on the grounds beside the covered communal area. From the balconies of the high-rise apartment complexes across a small glacial stream, rocks were thrown at the Colony pretty regularly.

“They don’t want them here,” Pugwat explained, “They don’t want to pay for a new and modern condo only to look out their window and look over a leprosy colony. They don't want to work hard and then see beggars on their streets.”

When I asked why, I received a similar answer to the candle story- because they were dirty. This description of ‘dirty’ conveys the same meaning and value that labeled of ‘sin’ carry within the context of leprosy. Although this lexicon of stigma vernacular has shifted, yet the application thereof perpetuates many of the same underlying prejudices against individuals with the illness and the disease.
Meals are communal at the Indresh Colony. The seated figure is the democratically elected president of the colony.

The modern stigma of leprosy in India, informed by perceptions of dualistic folk and western biocultural narratives, impacts marriage, employment, and specifically interpersonal kinship relations (Van Brakel 2003). One study suggests that their spouses on account of the stigma of disease, and not the disease itself, abandoned one in three patients with leprosy (Scott 2000). The socioculturally equalizing agent of leprosy stigma transcends kinship limiting caste distinctions, allowing for in the landscape of a colony, individuals with a common stared experience of disease come together and construct a fictitious kinship network, complete with marriages and families, that reach across social, cultural, and national identities, to make a ‘Parivara’ or family. The Parivara is united by
the very social stigmas and biological circumstances that caused abandonment events based in fear and socialized stigma towards leprosy.

“Why would I go back [to Nepal]?” a resident asked me, “I don’t want to see any of them [Nepalese family]. They abandoned me. They told me to leave and I did. This is my family now.. There is no caste here; caste doesn’t matter. We are all a family”

This statement was echoed by laughter and agreement from other residents listening to the conversations.

In the landscape of the leprosy colony, individuals are linked by the common social stigmatization of leprosy and come together to create socialized kinship networks that embrace the individuated challenges of HD to create their ‘parivara’.

The group norm of contextualized modernity of the upwardly mobile and educated urban classes thus assembles the experience of leprosy as not only inherent with diverse representations of sin, but informed also as a visual representation of ‘anti-modernity’ from folk-informed understandings of their own illnesses. The stigma remains, yet the social metaphors and logics of folk leprosy are replaced by contextualizing and transliterating symbolic Western constructs of modernity through educationally institutionalized empiricism and nationalism.

This application of stigma intensifies when seen through the framework of a society with historically rigid sociocultural boundaries of India’s caste system. Within the power differentials of this stratified society, the stigmatizing agent of leprosy transcends social castes and creates a marginalized society of ‘others’ abandoned by traditional kin relations. And yet within these leprous communities, new kinship structures are formed and maintained, creating socialized sanctuary and modest actualized independence
despite their exclusion from society at large. However, opposing these crafted familial support structures of the colonies are a broader denial of the endemic disease in the non-infected population. The guide’s denial and description of those with leprosy, having no where else to stay, sleeping along the streets leading of the marble mausoleum, reinforces an identity constructed using symbols of modernity, or India joining the world in a post post-leprosy and ‘modern’ time, as well as using of the prejudicial ‘dirtiness’ of the residents of the colonies. These constructed presentations to those traveling to India externally and internally reinforce the distorted and dogmatic enduring presence of the stigma.

Within the socialized landscape, the construction of a fictitious family structures, united by shared biocultural relationship of illness informed identity, is supported by the therapeutic landscape of the colony being not only a place of physical healing from the disease, but also a place of spiritual and psychosocial healing from the creation of a space in which their illness is not stigmatized, but normalized. The construction of this therapeutic landscape in an urban environment puts the entity of the colony, and the community there within, at geographic odds with the surrounding community, highlighting constructs of urbanization and modernity as seen by the construction of luxury apartments surrounding the colony.

And yet the ways in which individuals with leprosy, living in a rapidly industrializing Indian society, contextualize kinship based upon assumed structural, though not gender, equality mirrors the very goals of ‘Modernization Initiatives’ structurally and socially enforced. But this constructed equity is not recognized due to historically informed and culturally propagated stigmas identifying those with HD as the
‘Other’, and therefore existing in contradiction to their modernity-informed ‘Self’ (Jensen 2011). And so, leprosy exists as one of the most feared and forgotten maladies in the history of mankind. The medieval images of social isolation and leprosarium’s filled with elderly peasants ringing bells and trailing body parts are disturbing constructs carelessly reinforced by countless works of literature and film. Indian and Western cultural stigmas and understandings of those with HD equate the bacterial pathogen as a physical manifestation of a sin against God, and therefor construct understandings of the biology of the disease as moralized and socialized identifications of Other. But perhaps the most insidious aspect of the disease is the belief that is it extinct. This pervasive understanding that leprosy does not exist outside the pages of a history book, and is not an active and stigmatizing reality for hundreds of thousands, yields minimal efforts to eradicate leprosy, one and for all, from the human pathogenic profile.
A temple was donated and built in the colony so the Hindu residents, who are not permitted to enter public temples, have a space to practice their religion.

Pugwat (third from the left) and myself with residents after interviews were complete.
Faces behind the Stigma: Portraits of Residents
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